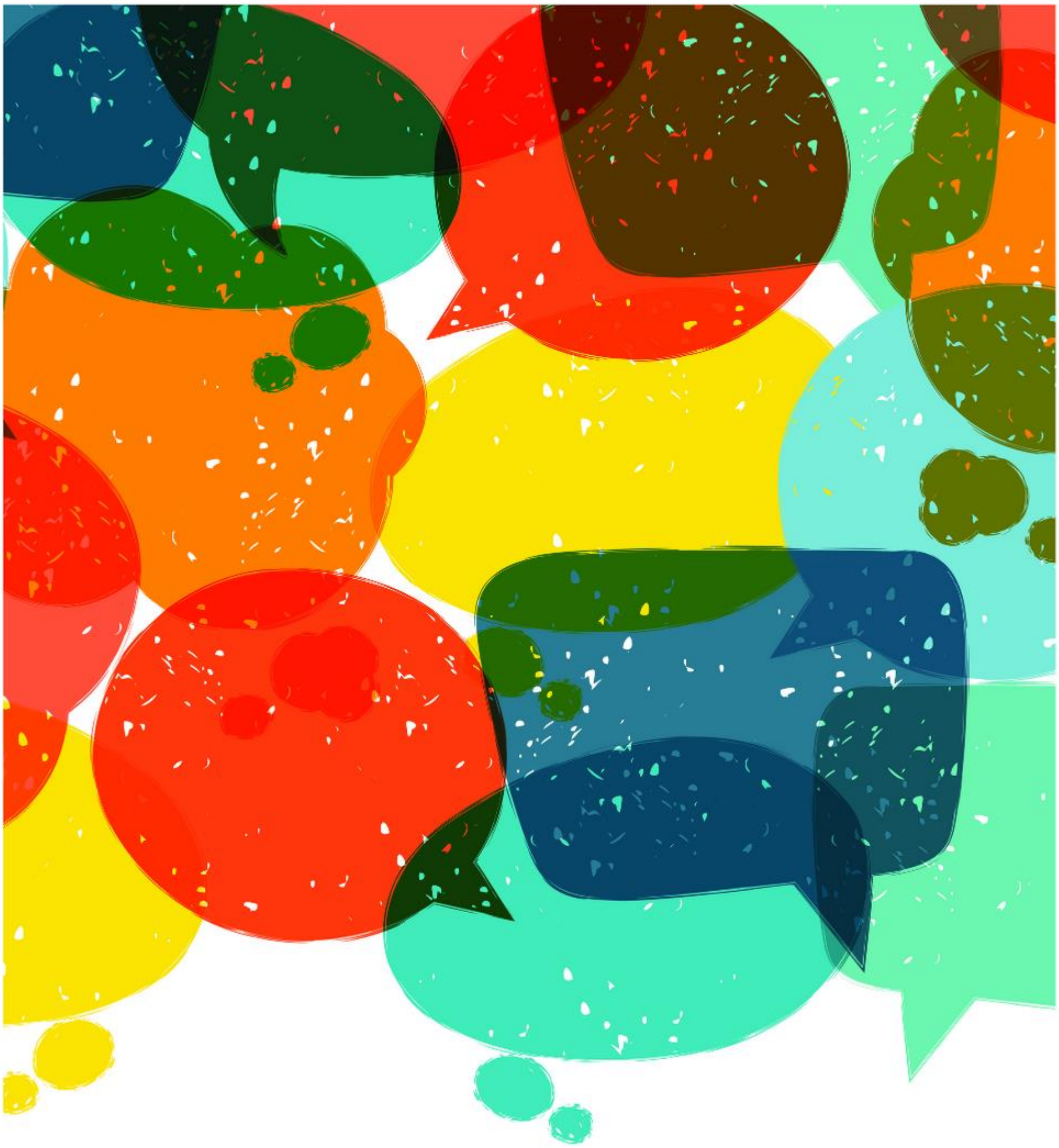

Dementia care in 2035

Final report from scenario project

Teknologirådet

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The scenarios are part of the Assisted Living Project (ALP) a four-year research and development project, led by OsloMet - the Metropolitan University, which aims to promote responsible research and innovation in the field of assistive technology. ALP is funded by the Research Council of Norway, under the SAMANSVAR program, in collaboration with the ICTPLUSS program.

PROJECT BACKGROUND

Today, approximately 80 000 Norwegians are diagnosed with dementia, and that number will likely double by the year 2040. Cognitive impairment and dementia cause extensive use of health- and care services, which will constitute an increasing societal challenge in the coming years. Society and politicians are facing munerous difficult decisions, and sometimes conflicting needs, when developing policies for an aging society. Predicting the outcomes of these decisions can be very difficult.

Therefore, scenarios can be a good method for exploring the manouvering room and find the key questions that must be addressed. We have created three scenarios for how Norway's dementia care can look in 2035.

DEVELOPING SCENARIOS

Based on the ongoing rapid technological development, the time horizon for the scenarios was set to 2035. In a workshop with the Assisted Living-project's reference group, both small and grand developing traits that will affect future dementia care were discussed. Next, an expert group was formed to continue working with the inputs. The developing traits that were considered most likely were selected as a starting point for the design of the scenarios.

The expert group consisted of:

- Torild Holte, National Advisory Unit for Aging and Health
- Erik Thorstensen, Center for Welfare and Labor Research
- Patrick Waldemar, Telenor
- Marianne Barland, the Norwegian Board of Technology

Project manager: Adele Flakke Johannessen, the Norwegian Board of Technology

THE SCENARIO WORKSHOP

We gathered resource persons from the health- and care sector, the business sector, academia and various interest organizations to discuss the scenarios and field suggestions for visions and policy recommendations.

Facilitating for the involvement of a wide range of relevant stakeholders contributes to a nuanced discussion where more groups than merely the normal experts are included. Such qualitative methods does not provide concrete answers but the discussions can be a good indicator of the attitudes to possible alternative choices of action.

The scenario workshop aimed to identify different opportunities and dilemmas we can be facing in the future. After the discussions, the participants formed groups and formulated possible suggestions for action to the politicians.

BACKGROUND AND FUNDING

The background for the scenarios «Dementia care in 2035» is the Assisted Living-project (ALP). ALP is a four-year research and development project, led by OsloMet – Metropolitan University, which aims to promote responsible research and innovation in the field of assistive technology.

The project is funded by the Research Council of Norway, under the SAMANSVAR program, in collaboration with the ICTPLUSS program.

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INTRODUCTION

Cognitive impairment and dementia cause extensive use of health- and care services and will constitute an increasing societal challenge in the coming years.[1] We have created three scenarios for how Norway's dementia care can look in 2035.

WHAT ABOUT THE FUTURE

Artificial intelligence, digitalization and other technologies are entering the health- and care sector and can significantly impact dementia as a disease as well as dementia care. Examples include opportunities for early diagnosing, delaying progression of the disease, personalized follow-up, decision-making support both for next of kin and health personnel, better utilization of resources in the services and monitoring of the disease.

The purpose of scenarios is to develop awareness around the decisions we can make today in order to be better prepared for the future. The scenarios are not aiming to predict the future, but rather serve as a starting point for discussing the choices we are facing today and future policies in the health- and care sector.

DEVELOPING SCENARIOS

Scenarios are plausible and knowledge-based stories about the future. They function well as a tool for discussing various future alternatives. Are municipal health- and care services ready to meet the needs described in the scenarios? What is the maneuvering room, and what are the key questions that must be addressed by politicians in the coming years?

THE REPORT'S STRUCTURE

Chapter 2, «Why dementia?», describes the various stages of dementia, prevention and diagnosing. In chapter 3 «Developing traits», we highlight the most important drivers within demography, economy and particuarly technology. Lastly, we look at the two most uncertain traits, which creates the axis cross. In chapter 4 «Scenarios», we meet three individuals in three different scenarios for dementia care in 2035. In the final chapter «Scenario workshop» the results from the scenario workshop are presented. Here, we dive into the most important discussions and present suggestions for actions for the politicians.

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[1] https://www.fhi.no/nettpub/hin/ikke-smittsomme/demens/

WHY DEMENTIA?

Today, around 80 000 Norwegians are diagnosed with dementia, and that number will likely double by the year 2040.[2] In the coming years, many of us will be affected by dementia in some way – either by developing it ourselves or because someone we care about will.

WHAT IS DEMENTIA?

Although dementia is something that commonly affects the elderly, it is not a normal part of the aging process. Dementia is caused by various brain diseases and is characterized by cognitive malfunction, emotional and personality changes, and difficulties functioning in everyday life. The loss of cognitive and motor functions, alongside additional mental symptoms such as anxiety, depression, and delusion cause much suffering for those diagnosed with dementia.[3]

Dementia may also negatively impact close family members. It is well-documented that caregivers have an increased risk for developing health problems and mental symptoms.[4,5]

Many different illnesses can lead to dementia. However, the majority of dementia cases develop in two ways. Most commonly through Alzheimer's disease, where brain cells are damaged for reasons we do not know yet. Vascular dementia is the second most common leading cause, and can be a result of a clogging or narrowing of the brain's blood veins. Approximately 50-60% of the dementia diagnoses are a result of Alzheimer's disease and around 25% through vascular dementia. Other causes may be through a series of other diseases.[6]

DIAGNOSING

As of now, there is no simple test that can determine whether a person has dementia or not. Doctors must rather assess a variety of factors, such as a patient's medical history and observations reported by family members or health personnel. Early diagnosing can help scientists develop medicines to slow down the progression of the disease.

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[2] https://nasjonalforeningen.no/demens/hva-er-demens/

[3] https://www.fhi.no/nettpub/hin/ikke-smittsomme/demens/

[4] https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-016-0403-2

[5] https://www.ncbi.nlm.nih.gov/pubmed/18924398

[6] https://legeforeningen.no/Emner/Andre-emner/Publikasjoner/Statusrapporter/statusrapport-om-situasjonen-i-helsetjenesten-nar-du-blir-gammel-og-ingen-vil-ha-deg/kapittel-2-kunnskap-om-eldre-og-eldres-sykdommer/

Companies, universities, and research institutes within the health sector are using artificial intelligence for more efficient diagnosing and a less costly process.

In Great Britain, a group of scientists found that signs of dementia can be noticed several years earlier by using patient data and machine learning.[7] This is because the machines have a much greater capacity to recognize patterns that would otherwise be overlooked by humans. Research also suggests that machine learning and voice recordings can be used in diagnosing.[8,9]

More knowledge about how dementia occurs and develops will make it easier to develop a cure. However, a cure is likely many years away.

Stages of dementia

The disease manifests itself differently between individuals. Symptoms may vary in terms of when they occur, in what order, and in intensity. The duration from when the frist symptoms are discovered to the patient dies also varies. For some it may be four or five years, for others it may be 20 years.[10,11]

Mild
- Memory impairment (particularly short-term memory)
- Reduced spontaneity
- Loss of perspective of time
- Struggle making decisions

Moderate
- The person needs help to function in everyday life
- Forgetting to eat regularly
- Need assistance with personal hygiene, getting dressed, cooking, and personal economy
- Reduced sense of direction, gets lost in local area
- Problems with coordination and language
- Can be a danger to their own safety (e.g. forgetting to turn of the oven)

Serious
- Total dependence on others
- Fails to recognize family members
- Obvious loss of memory
- Problems walking
- Needs help eating
- Urinary- and bowel incontinence

PREVENTION

Aging is the most central risk factor for the development of dementia, while genetic predisposition is number two. These are factors we have very little control over. Lifestyle and living conditions are other risk factors that we can influence to a much larger degree.[12]

Many protective measures are concurrent with heart- and cardiovascular diseases: a healthy diet, physical activity, non-smoking, and controlling blood pressure and cholesterol. A stimulating environment is also important. Diabetes is another risk factor.

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[7] https://bjgpopen.org/content/bjgpoa/early/2018/06/06/bjgpopen18X101589.full.pdf

[8] Toward Dementia Diagnosis via Artificial Intelligence By Frank Rudzicz, PhD. Today's Geriatric Medicine. Vol. 9 No. 2 P. 8

[9] http://www.catch.org.uk/current-project/automatic-analysis-of-speech-and-language-dementia/

[10] https://nasjonalforeningen.no/demens/symptomer-og-tidlige-tegn/

[11] https://www.aldringoghelse.no/e-l%C3%A6ring/palliasjon-og-demens_/modul-demens-og-palliasjon/utvikling-av-demens/#3

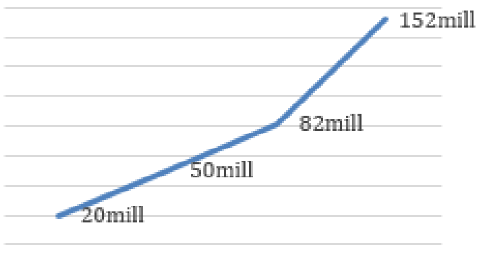
[12] https://www.regjeringen.no/contentassets/3bbec72c19a04af88fa78ffb02a203da/demensplan_2020.pdf

DEVELOPING TRAITS

In these scenarios we have examined some strong drivers and emphasized demographics, economy, and particularly technology that is likely to influence dementia care in 2035. First, we will present three traits we are quite confident in and two developing traits we are unsure of.

AN AGING POPULATION

In the years after 2030 we will really start to see the impact of the aging population. The proportion of elderly will be particularly high in the districts.[13] This will have some vital consequences:



Persons with dementia from 2019-2050 (WHO)

- **More living with dementia:** Dementia occurs with age. This means that when the number of elderly increases, so does the number of people living with dementia. In Norway, we expect a doubling from 80 000 to 160 000 in 2040.[14] Many of us will come in contact with dementia – either because we develop it ourselves or because someone near us will develop dementia.
- **Healthier elderly:** More people stay healthy longer and places higher demands on the welfare services. This means that demands are increasing, but more importantly, it influences what is demanded.[15] The new elderly will happily contribute, but their efforts need to fit into daily routines.
- **Stronger aging in the districts:** The trend shows that young people in fertile ages move to the city, and consequently, more children are born in central areas. The elders stay in the districts, and in 2040 more than every third resident in district municipalities will be over the age of 70.[16]

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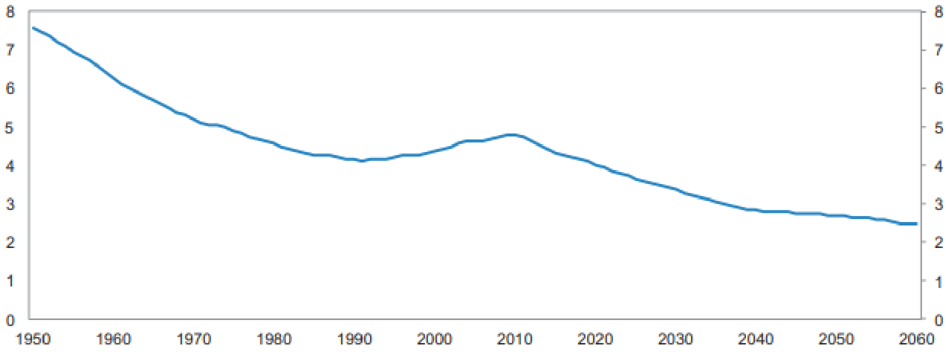
[13] https://www.ssb.no/befolkning/statistikker/folkfram/aar
[14] https://nasjonalforeningen.no/demens/hva-er-demens/
[15] Slagsvold & Solem, 2005
[16] https://www.ssb.no/befolkning/artikler-og-publikasjoner/lavere-befolkningsvekst-framover

PUBLIC RESOURCES UNDER PRESSURE

- **Lower income** from the oil- and gas industry and the pension fund. In the coming years, the expenses of age- and disability pensions in the social insurance scheme will surpass the income of the fund. This can lead to an increase in the household tax burden by up to 65% in 2060 to maintain the same level and organization of welfare services as we have today.[17]
- **Fewer workers:** Today, there is bipartisan agreement that health- and care services should be financed by the public, and we predict this will still be the case in 2035. The challenge is that there will be fewer workers per retiree.[18] If we want to continue to deliver services with today's quality, we must reorganize the services.



Number of 20-66-year-olds compared to 67 years and older (The Commission of Productivity)

TECHNOLOGY TRENDS

- **Smart surroundings:** While the third generation (3G) gave us data and smartphone apps, and the fourth generation (4G) gave us video streaming, future communication technologies (like 5G and 6G) will give us a lift across several dimensions: 5G guarantees the delivery of messages (alarms), less time-delays, and 10 times the bandwidth of today. This facilitates for the use of the internet of things to a much larger degree than before.

  We will have the possibility of wearing technology (figure-hugging sensors) and bringing it into the home (ambient sensors), which will provide better opportunities for distance monitoring and measuring (e.g. weight, blood pressure, and medication).

- **Artificial intelligence:** Machines are now learning to interpret text, speech, and images, as well as perform tasks that were previously reserved for humans. Interactions with the machines are also happening in new ways: From symbols to speech, movements, and expressions. Artificial intelligence facilitates emotional, cognitive, and physical support from machines:

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[17] https://www.regjeringen.no/contentassets/64bcb23719654abea6bf47c56d89bad5/no/pdfs/nou201620160003000dddpdfs.pdf
[18] https://www.fhi.no/nettpub/hin/befolkning/befolkningen/

  - **Cognitive and emotional support:** Advanced analyzing tools can use different types of data and machine learning and learn to adapt to a patient's condition. Digital assistants (e.g. Amazon's Alexa or Apple's Siri) that both listen and speak, can be used to help people with dementia to remember, make decisions, and organize their daily lives. They can also provide decision support to healthcare personnel and next of kin.

  - **Physical support:** Robots can help with several physical tasks such as using the restroom, showering, clean, cutting the grass, or support healthcare personnel with heavy lifting.

  - **Diagnosis:** As the machines are much better at pattern recognition and have much greater access to data, they can help diagnosing several years earlier than before. Earlier and faster diagnosing provides opportunities for better treatment and subsequently cutting costs. It can also help scientists in developing medicines to slow down the progression of the disease.

- **New actors:** Digitalization leads to a re-organization of actors within the health sector. Volunteers can perform new tasks, new companies can enter the market, and the role of the public sector changes:

  - **New ways to organize services:** The sharing economy provides new opportunities for coordinating different services. Time banks (time tracking systems for volunteers) supplies the public services of today. People deliver services for free and get paid in hours in time banks. The hours can be used for other services. This makes people more active and participating in their local communities.

  - **Platforms give power:** The health sector is beginning to resemble the internet-economy, which is based around trading personal data. Data will be an important currency and platforms such as Amazon, Apple's Appstore and Facebook will be used as distribution channels by many different actors. The ones controlling the platform will have a lot of power as they have access to large databases of personal data.

DEVELOPING TRAITS WE ARE UNSURE OF

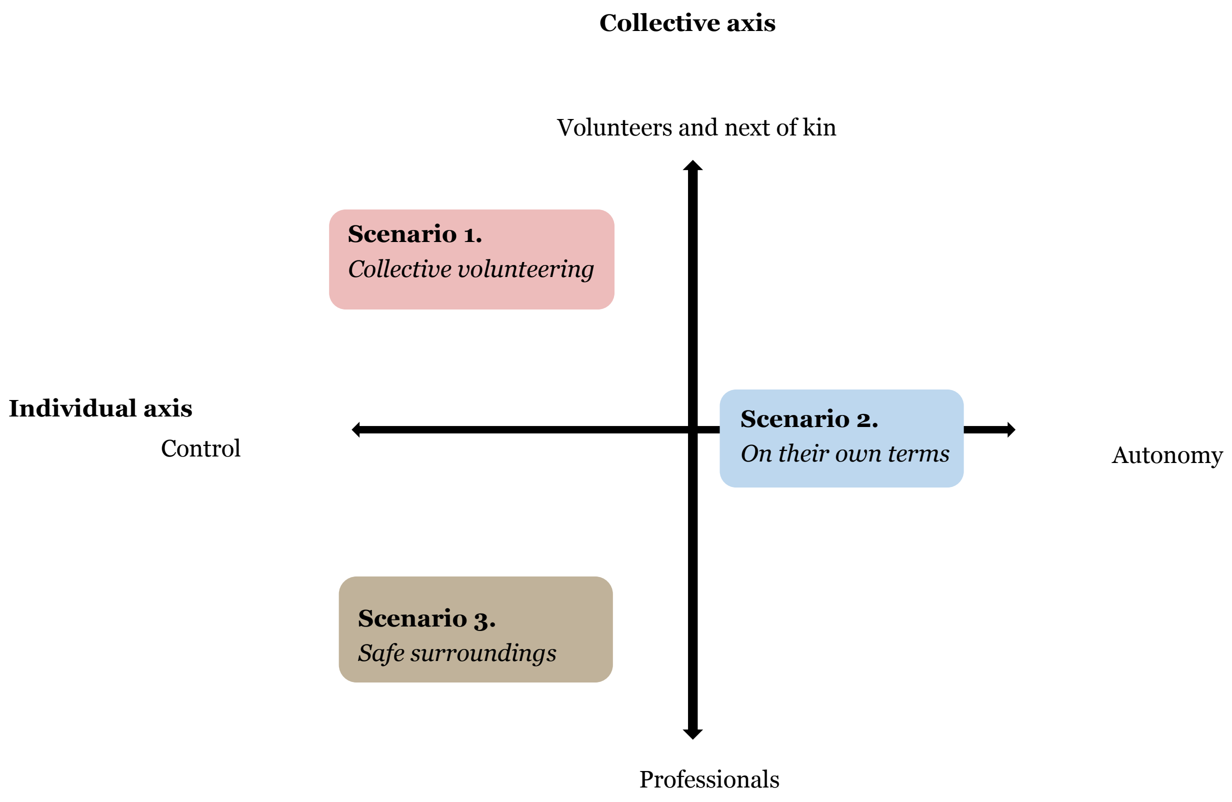
These are questions that we do not know the answer to, but where political decisions will have considerable influence.

- Collective axis: How are we going to organize work?

- Individual axis: What do we value the most – control over the disease or autonomy?

In the figure on the following chapter, we have placed the two questions along two intersecting axes. The vertical axis considers the question of how to organize work. Here, we have placed large public service models that focus on professionalized services versus a model where the public functions as a platform and next of kin and volunteers are the ones that perform the actual services. On the individual axis, we look at the value of having control over the disease versus the value of autonomy. The solution will be somewhere between these extremes. However, we want to push the window of opportunity as far as we can in order to prepare for the future in the best possible way.

SCENARIOS



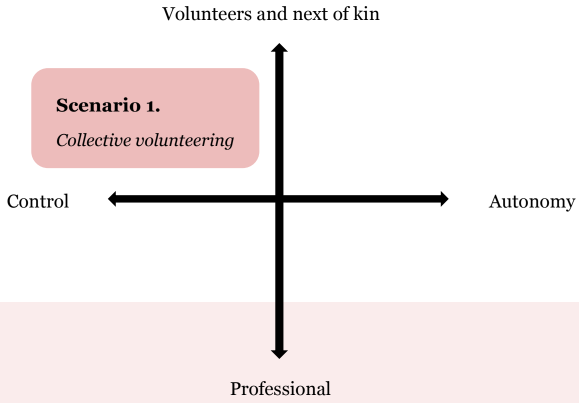
The three scenarios are put together by combinations of the extremes mentioned above, and illustrate different ways society can develop depending on what choices are made and what values are prioritized. In each scenario you will meet one or more fictive characters. Their stories aim to show how political decisions create opportunities and dilemmas for persons with dementia, next of kin, volunteers, healthcare personnel, and society at large.

Scenario 1: *Collective volunteering* is based on volunteers being the main resource for people with dementia. These can be their families, charitable organizations, neighbors, students, and so on. The local governments are in charge of coordinating the resources. Technology is used to monitor the progression of the disease and provide personalized care.

Scenario 2: *On their own terms* is based around the person with dementia and the need for autonomy and interaction. Volunteers deliver different services and is paid through the municipality's time banks. Technology is used for and with the person with dementia.

Scenario 3: In the scenario *Safe surroundings,* Norway places a systematic focus on early diagnosis and prevention through the dementia program. The municipality's role is to ensure consistent supervision and data collection through new technology.

SCENARIO 1: COLLECTIVE VOLUNTEERING



IT IS NOW 2035 AND THIS HAS HAPPENED SINCE 2019:

- **Strong pressure on services:** In 2025, the impact from the aging population was really felt in Norway. The municipal care services were pressed, and tough prioritizing had to be done in order to maintain sufficient standards on the services. The municipalities have re-organized and re-distributed the responsibility between professional healthcare workers and the next of kin, alongside investing heavily in technology.
- **Next of kin becomes responsible:** Next of kin receive compensation if caring tasks take away time from their regular job. They have their own support groups and must participate in mandatory courses. More funds are also allocated to volunteer organizations that ensure activity among the elderly and the people with dementia.
- **Digital takeover:** Primary care doctors are replaced by a digital frontline. All residents have personal digital assistants provided by the municipality. When they need health support, they can perform measurements via their smart phone and from sensors in the home and on their bodies. If something seems out of the ordinary, they can ask the digital assistant for help and advice. The digital assistant can also arrange for a doctor to come check up on you or schedule an appointment in one of the local health centers, if needed.

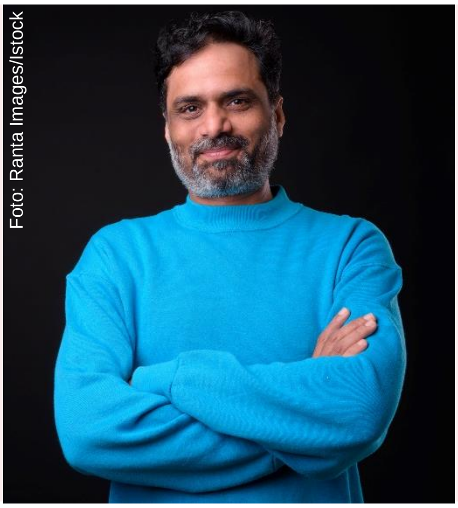


Foto: Ranta Images/Istock

Jonas (45) is married, has two children and works as an accountant. He is also responsible for his mother Sunita.

Sunita (75) has moderate degree of dementia and diabetes.

Here is the story of how Sunita received the dementia diagnosis and how Jonas had to take care of her:

Almost four years have passed since the digital assistant «Alex» reported changes in speech and behavior for the first time. It was a Tuesday morning and Sunita was enjoying her morning coffee when the little speaker said: «Good morning, Sunita. It is a sunny day with blue skies and 10 degrees outside. Your insulin levels are normal, but I noticed some irregularities in your speech and have scheduled a phone appointment with the doctor at 13.00. Do you wish to confirm?». Sunita felt agitated and cancelled the appointment. The next few days she kept on thinking about what «Alex» had said. Wasn't this what they had learned at the health center? Speech impediments and language difficulties could be the first signs of dementia. After some consideration, she disregarded the thought and continued with her day.

As the months went by, the symptoms worsened and, even though Sunita tried to hide it, the algorithms caught it. «Alex» booked another appointment with the doctor, this time without asking for Sunita to confirm. After a thorough examination, Sunita was diagnosed with a mild degree of dementia and was asked to inform her next of kin.

Her son Jonas had been worried about his mother for some time but had thought that indecisiveness and poor memory were just natural parts of the aging process. Although he felt a bit relieved to get an explanation for her behavior, Jonas still knew that his mother was going to be increasingly dependent on him.

Shortly after Sunita was diagnosed, Jonas got called into a meeting at the municipality to discuss both his and his mother's future. At the meeting, Jonas was informed of mandatory courses and was given a support group consisting of other «new» next of kin. They were planning regular meetings at the health center throughout the first year but could communicate digitally if needed. The support group is organized by volunteers.

After finishing the course, Jonas wanted to apply for care pay to take care of his mother. He was also recommended to create a profile on the application RO – a digital assistant that communicates and provides advice if one experiences stress, anxiety, or loneliness. It can also assist with everything from breathing exercises and reflection tasks, to customized music tips. The data collected by the RO-app was turned into a score. Low score over longer time periods would be followed up by the municipal health services. Jonas saw the RO-app as some sort of a digital psychologist, similar to how «Alex» functioned as a kind of health- and care worker.

In order to live at home and receive close attention, Sunita got a variety of sensors installed. Infrared sensors were placed in different spots in her home. These were installed by volunteers from the municipal technology group the same day as she received her diagnosis. Jonas was informed that the sensors at home would be able to track her movement patterns, sleeping and eating habits, and predict wandering and falling. In addition to the sensor in her home, Sunita got a ring enabling her to speak to «Alex» wherever she was located, and «Alex» always knew her location and could help guide her home.

The data from the various sensors were made available for Jonas and he was provided access to «Alex», his mother's digital assistant. Via «Alex», Jonas received notifications if his mother exhibited irregular behavior, could get guidance and decision-making support, or be notified to contact a doctor.

Sunita thought she would feel watched, but since she knows that only her son can monitor what she does and what happens with her, she feels the technology provides security. She is happy that she only has to deal with Jonas.

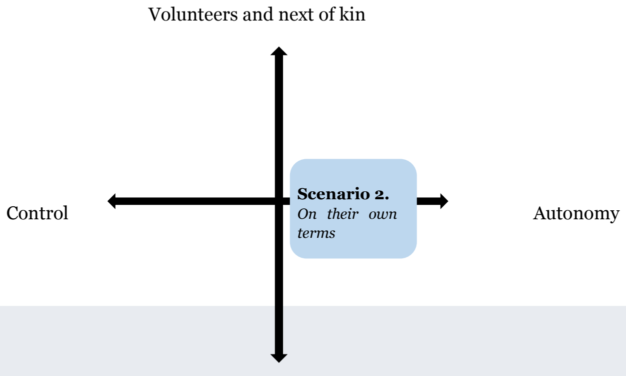
Despite the training and various online instructional videos, Jonas feels that it is difficult to interpret the health data from his mother, and not always easy to get ahold of a doctor if he felt unsure of what to do. Normally, he follows «Alex's» advice, but one time he disagreed with «Alex», which made him realize how much the health care system was based on automatic decisions centered around data. Without a recommendation from «Alex» it was nearly impossible to get ahold of a doctor. Jonas became frustrated and felt powerless. What if «Alex» was wrong, and he ended up giving his own mother the wrong medication?

Jonas ended up with walking down to the health center and stand in line for several hours, just to get the same advice «Alex» had given. At that moment, Jonas had such a low RO-score that he was booked to an appointment with an actual psychologist. It was comforting to speak to an actual person in the health care system. He was also informed of a volunteer group that helped next of kin interpret the data from the various sensors. This was a major help.

Jonas appreciates his care pay as it allows him to spend time with his mother. During the last few months, his mother's condition has gotten significantly worse. She is depressed, har poor appetite and do no longer want to participate in the activities provided by volunteers in the community. This has intensified Jonas' care work and he is experiencing trouble following up his own children and his regular job. He applied for his mother to get a spot in the dementia village but was declined since his mother's condition was, according to the data, not serious enough yet. Instead, the mother was given a robot dog, that had shown to increase overall life quality within elderly with dementia.

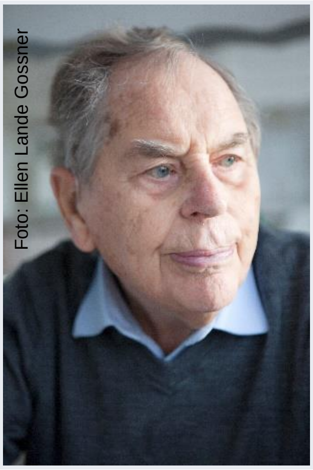
Although the mother thoroughly enjoyed the robot dog, Jonas still felt it was a bit demeaning. When «Alex» a couple months later reported that the mother was no longer capable of living at home, Jonas felt relieved. His mother was no longer herself and showed little interest in her grandchildren and Jonas when they came to visit. The only thing his mother cared about was the «dog». In less than a week after «Alex» had given the report, the mother was moved into the dementia village. Volunteers helped with moving, washing and selling the apartment. Two months later, Jonas was back at his full-time job as an accountant and his RO-score went back to normal.

SCENARIO 2: ON THEIR OWN TERMS



IT IS NOW 2035 AND THIS HAS HAPPENED SINCE 2019:

- **Resistance to digitalization:** The comprehensive digitalization of society at the beginning of 2020 generated counter reactions. People reacted negatively to more self-service initiatives and the increasing automatization in the healthcare system. In the 2029 election, the Senior Party received much support, and were able to introduce new health regulations in the care sector. These included the right to withstand from getting measured and analyzed, and the right to have meaningful human contact. To accomplish this, the municipalities have assigned shared responsibility between health care personnel and volunteers.
- **Aging plan:** Autonomy and participation are strong values in the health sector. To accomplish this, everyone writes an aging plan when they turn 75.
- **Dementia friendly society:** The government has invested heavily in educating the public regarding dementia and facilitation in society. There are different e-courses and simulations to make it easier for people to notice changes in behavior, and learn how to act around people with dementia.
- **Generation villages:** Since 2020, there have been built generation villages. Here, students, families with small children, and elderly live alongside each other. By gathering multiple people in one place, it is easier to make sure that everyone is seen and that they receive the help they need and are entitled to, while simultaneously reducing costs. Many were skeptical in the beginning, but incentives such as cheaper loans through the House Bank and free kindergarten spots have made these offerings very popular.
- **Volunteering:** There is a strong desire to ecourage residents to engage in volunteer work in the local community. Several of the volunteer services have been implemented in the municipal time banks. The work is registered in hours, and the volunteers can use their earned hours to purchase other services.



Jon (77) is a widower and a retired teacher. When his wife Kristin died, Jon sold the house and bought an apartment in a generation village. His daughter Julia is a chef and lives in the USA with her husband and their three children.

Two years ago, Jon suffered a stroke and was subsequently diagnosed with dementia. Before the stroke, Jon volunteered as a private tutor. By doing so, Jon collected points in the municipal time bank, which he now can spend on other services.

Jon is very happy with living in a generation village. There are many young people living there. One of them is Tom, a second-year engineering student. When Tom moved there, Jon had just received the dementia diagnosis. Jon had informed the board of his diagnosis and they connected him with Tom. Tom had taken a course in order to volunteer as a visiting friend. Students and recent graduates get cheap housing in generation villages in return for volunteering at least 5 hours a week.

One of the first activities Jon and Tom did together was creating a digital photo album. Tom had learned that photo albums could provide a glimpse into a person's life before the disease, and could benefit both the person with dementia, their next of kin, and health- and care personnel. Jon and Tom became good friends while working on the album, and Jon spoke about hobbies he had and about life with Kristin and his daughter.

Jon also spoke about his job as an IT- and social science teacher in the early 2020s. Here, Jon had witnessed several serious instances where students' personal data had been misused, which caused some students difficulties getting hired in the later years. This got him involved in the Senior Party and their fight for the right to not be assessed and analyzed.

Jon and his visiting friend Tom developed a strong bond and used to go for walks during the weekends and play cards or watch soccer in the evenings. But after three years, Tom finished his degree and moved out of the country for work. Since then, Jon has had many different visiting friends. Most of them have been nice and he gets the help he needs, but none of them knows him as well as Tom did.

When Jon was diagnosed with dementia, he got a robot from the municipality that could help him in many ways such as vacuuming, help with picking out TV channels, maintain order in the calendar and medicines, and challenge him to go for a walk. The municipality also installed fall detection sensors. For that to work properly, Jon was recommended to connect it to the home-service, but Jon did not wish to transmit data out of the house. The fall detection sensor has therefore yet to be activated. The robot can connect to the home care service and the doctor for faster help and better follow-up, but Jon has chosen to deactivate this function.

Since Jon does not want to share data with the home care services, it is difficult for them to coordinate their resources. Therefore, it may take longer for Jon to get a visit from the right health care professionals, and they have to spend a lot of time to read his historical data during the visits, rather than already knowing what measures have been implemented before they arrive.

Jon really has the capacity to live by himself but feels down and does not have the energy for doing more than the bare necessities. The days are unpredictable and he worries about the future. Maybe he should have let the health care personnel install some sensors after all?

His daughter Julia and his grandchild makes a visit from the USA. They have seen that Jon is feeling down and have brought a robot dog as a gift. His daughter explains that in the USA, robot dogs are just as common as regular dogs. Jon is initially skeptical but softens when he sees how much fun his grandchild has playing with the dog. They name it Fix.

80 % of the population (above the age of 16) contributes by working in volunteer organizations annually. This is the highest share measured on a world basis. Norway has surpassed Sweden.

NTB (2035)

Jon is surprised with how effectively Fix cheers him up. Fix also attracts attention when Jon takes it for walks. Kids want to play with Fix. Jon likes when children contacts him and asks him questions. Adults are also asking about where he got his «dog» and how it works. Jon gets out of the house more often and has more energy. He starts to use the other daily services delivered by the volunteers in the municipality and Fix is always with him.

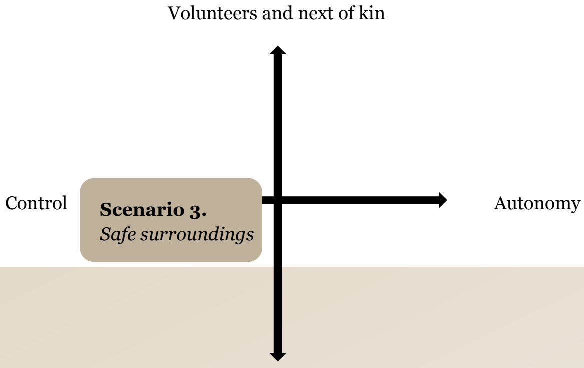
When his wife Kristin passed, Jon asked Julia if she could be his legal guardian if he were to experience problems with decision-making. They also discussed how Jon wanted his aging process to unfold and put together an aging plan. Privacy, autonomy, and getting to live at home were important for him.

As Jon required increasingly more assistance, Julia tried bringing up the idea that it might be easier for them both if he allowed healthcare personnel access to his data. This way he could receive closer attention and better treatment. But Jon refused. He wanted his privacy. Finally, Julia decided to go against her father's wishes and sent the sensor data to the health services.

After some weeks, she received a phone call from the municipality, thanking her for sharing the data. Apparently, Jon suffered from more than dementia, which would have been difficult for her to see. They proceeded to change his medication, which made him feel less apathetic. Since he already lived in a generation village where the infrastructure was good, the recommendation was for him to continue living there under close supervision from the health services via sensor data. His daughter felt reassured knowing that her father was in good and safe hands.


Photo: Ellen Lande Gossner

SCENARIO 3: SAFE SURROUNDINGS



IT IS NOW 2035 AND THIS HAS HAPPENED SINCE 2019:

- **State governance:** As a consequence of the large municipal discrepancies in purchasing- and ICT competence, the Ministry of Health and Care Services have taken greater control over the municipal health- and care services. The municipalities are put under stricter financial regulations. Through tender arrangements, the Government has selected three technology providers that the municipalities can choose from. In 2025, the Dementia Program was started. Systematic data collection and use will aid the municipal health services exploit their resources optimally.
- **The Dementia Program**: When the Norwegian Medicines Agency approved a medicine that could delay dementia up to five years, the Government initiated a screening program. As society saves millions by delaying dementia by only one year, all citizens were strongly encouraged to go through the screening when they turned 65. The results decide what actions need to be taken and the data is stored and used to improve the diagnostics and prediction algorithms. People were skeptical at first, but incentives such as personalized assistance and tax breaks increased participation.
- **Norway's digital nurse Annie:** The technology is implemented to relieve some of the pressure on resources in the care sectors. Digital assistants with audio interfaces collect information from a variety of sensors and dementia patients' journals. The information is used to ease the workload for health personnel, making it easier for them to provide better and more personalized treatments. The digital assistants are regular attendees in staff meetings.


Foto: Jakob Helbig/Istock

Tone (70) is married to Bernt (70). They live in their own apartment downtown in a large city. Tone and Bernt enjoy most of what life has to offer, especially exotic food, art and culture.

Tone has a son named Andreas (42) from a previous marriage. He lives in a big city on the other side of the country with his wife and child.

Here is the story from eleven years ago, when Tone found out she were going to develop dementia.

Tone has been mainly healthy her whole life, but a lot of her family members have suffered from Alzheimer's disease. Therefore, Tone has frequently taken cognition tests at helsenorge.no.

When Tone was 59, the test results indicated that everything was not as it used to be, and she was offered a full screening at the dementia center later that week. There, she got the future score of 17 out of 20, which indicated that she was very likely to develop dementia within the coming five years. However, research suggested that combining a healthy diet and working out regularly, with the right medication, could delay the dementia with up to five years. Tone was called into a meeting with her contact person in the municipal dementia team to discuss the future.

At the meeting, the municipality informed Tone that she had free access to the gym at the dementia center, as well as a training app with a personalized workout plan. She was also offered a discounted price on weekly food deliveries to her home alongside a variety of suggestions for dinner recipes.

Tone happened to live in one of 50 municipalities that were used for research on a cure for dementia. She was asked if she wanted to participate in one of the research projects. As a participant, she would be required to have a sensor attached to her arm that would constantly track her heart rate, blood pressure and insulin levels. She would also have sensors installed in her home that would record her voice to see if there were any changes. However, as these tests were done automatically, and she would not have to take any tests manually.

Tone was unsure if she wanted to participate. She was not sick yet, so it all seemed a bit much. Bernt was also skeptical to having all those sensors in their home, although he was assured that the sensors would only react to Tone's voice. Their son Andreas, on the other hand, was very positive. Since the family had a history with Alzheimer's disease, this type of research would benefit both him and his children. Tone had not thought of it that way before and she informed the municipality that she wished to participate after all.

Norwegians are happy to share data for research purposes and Norway is in pole position to solve the dementia mystery and find a cure.

NTB (2032)

It felt good knowing that someone was paying attention and keeping control of the development of the disease. However, Tone still struggled living normally during this period. She was very aware of all sorts of changes and felt ashamed when she forgot things. Her husband, Bernt, felt the future did not look as bright as before. They had looked forward to retirement and having the freedom to travel, experiencing new cultures, and enjoying new and exotic foods and beverages.

The sensors at home picked up on Tone's poor mood and she was called into a meeting with her contact person in the dementia team. Following, Tone and Bernt were offered visits with a psychologist with long experience with people who had been diagnosed with dementia early. The conversations with the psychologist were great help for both Tone and Bernt.

7 years later, Tone gets called into her doctor's office. The sensors have picked up changes. The doctor compliments Tone for working so hard and that she has likely delayed her dementia with four years. Unfortunately, it looks like she will develop moderate dementia within the next two years. But through the research project she had been a part of, she is given an opportunity to test a new medicine that can potentially delay the progression of the disease yet another year. However, it requires an even stricter diet and more sensors.

After a lot of thinking and many conversations with Bernt, Andreas, and her psychologist, Tone declines the offer. The recent retirees decide they rather wish to enjoy life instead. They know that Tone will develop dementia within two years anyway. The couple travel for over a year and develop an even closer relation. Shortly after they come back home, Tone develops poor short-term memory and becomes more aggressive.

After several tests at the dementia center, Bernt and Tone gets a new sensor that records Tone's voice. They also get optical sensors installed around the apartment that monitors vital signs, breathing and heart rate. Additionally, the sensors can predict a risk of falling. Notifications regarding changes in behavior and alarms go straight to the home care service and is stored in her patient journal via the health services' digital assistant «Annie». «Annie» also helps Tone remembering everything from taking her medication to birthdays. This makes daily life easier for Tone and she feels safe.

Bernt, on the other hand, thinks the sensors are a bit annoying. He feels watched. Bernt knows the assistant is there in meetings, and therefore the health personnel can know everything they have talked about or done. At the same time, it is good to know Tone is always safe and that professionals are taking good care of her. He has learned about dementia through his job and been told horror stories of what could go wrong if they did not get the help they needed.

In a staff meeting, «Annie» tells she has picked up from Tone's responses that Bernt is not feeling well. This is discussed the next time the dementia team visits their home. Bernt has felt a bit lonely lately because he does not feel right leaving his wife, even though he knows she is being monitored and that someone is always ready to help if something were to happen. He just doesn't want her to feel lonely. Together, they decide that the municipality will employ extra personnel one weekend every month so Bernt can feel free to do what he wants.

AT THE SCENARIO WORKSHOP

Society and politicians are facing numerous difficult decisions, and sometimes conflicting needs, when developing policies for an aging society. Predicting the outcomes of these decisions can be very difficult. Therefore, we have gathered resource persons from the health- and care sector, the business sector, academia and various interest organizations to discuss the scenarios and field suggestions, visions and policy recommendations.

The scenario workshop took place at the House of Literature in Oslo on October 17th, 2019 from 09.00-13.00. The participants were divided into groups based on background and competence, with one moderator in each group.

The workshop started with a presentation of the various scenarios before participants were asked to offer positive and negative feedback. Further, the groups discussed the opportunities and challenges related to the different scenarios. Lastly, the groups developed 2-3 suggestions for the politicians. After the scenario workshop, the suggestions were sorted by the Norwegian Board of Technology. The suggestions are italicized, while summaries of the group discussions are written in regular font.

SCENARIO 1 – «COLLECTIVE VOLUNTEERING»

In scenario 1, volunteers serve as the main resources for people with dementia. Volunteers can essentially be anyone e.g. family, charitable organizations, neighbors, students and so on. The municipality coordinates these resources. Technology is used to track the progression of the disease and provide personalized follow-up.

NEXT OF KIN AND VOLUNTEERS

Next of kin are crucial resources in scenario 1. The participants considered it beneficial for the person with dementia to have one specific person to interact with. However, they noted that society could suffer economic losses if it became too demanding resulting in next of kin also getting sick. Thus, the participants were positive to follow-up provided by next of kin but commented that today's offering was insufficient. Moreover, it was stated that follow-up through an application, as described in the scenario, was not adequate. Human contact is just as important for the next of kin as it is for the patient.

> *The health authorities should examine how digital solutions for follow-up and coordinating physical meeting places can provide support for the next of kin.*

The participants noted that we should be careful with making society too dependent on volunteers. It is not given that everyone has a close relative that can take responsibility, which could create social inequality. Therefore, a better division of labor between the volunteers, next of kin and health workers was recommended.

> *The Norwegian Directorate of eHealth must explore the opportunities of using platform technology in connecting key welfare services with available resource persons as a means to free up resources in the health sector. We should explore whether existing coordination- and communication platforms can be further developed, and subsequently distributed on a national level. Sound collaboration with the business sector will be important.*

Various incentives for increasing volunteer participation were also discussed. Several participants were positive to the idea of time banks and compensation, while others were skeptical to «paying» volunteers as it would confuse the concept of *volunteering*.

> *An interdisciplinary/intersectoral group selected by the Ministry of Local Government and Modernization must explore arrangements for compensation and flexibility to help others regardless of family relations. For example, coordinated by volunteer organizations. This could contribute to a more generous society.*

TECHNOLOGY IN FEDERAL PLANS

Welfare technology is likely enter homes independent of national health services. A mix of private and public sensors can create ambiguity in allocating areas of responsibility, causing health personnel having to work with multiple applications. The participants indicate that this can cause discrepancy within the population and that the technology must be employed in federal plans.

> *To ensure implementation of the technology of today (and of tomorrow), health officials must continue the federal welfare technology program past 2020, with earmarked projects funds (today, much relies on volunteers in municipalities) and requirements for involvement, to find sustainable solutions. Technology promoting a larger treatment capacity for health personnel should be in focus.*
>
> *The Government should to a larger degree include and evaluate the technology of today (and of tomorrow) in the systematic work with dementia plans.*
>
> *The Directorate of Civil Protection must ensure reliable Internet access for all. They must be able to guarantee that all alarms come through. This needs to happen now.*

SHARING DATA

Welfare technology collects data and information in order to function effectively. Therefore, it is important to develop clear guidelines for how data can be collected, which data can be used, and which is off limits. The participants highlighted the importance of establishing trust in that data is being used appropriately. It was iterated that health officials must work proactively to make both sharing and using data feel safe.

SCENARIO 2 – «ON THEIR OWN TERMS»

Scenario 2 centers around the person with dementia and focuses on the need for autonomy and involvement. Volunteers provide various services and are rewarded through municipal time banks. Technology is used both for and alongside the person with dementia.

INTEGRITY AND INVOLVEMENT

The participants believed involvement and co-determination will be increasingly important in the future. Most were positive to the idea of creating an aging plan alongside their next of kin where they can narrate how they want their aging process to unfold. Issues that can be addressed in an aging plan could, for example, involve if the person wants to live at home for as long as possible, or preferences regarding the use of technology and sharing data. In an aging plan one can reflect over wishes for the future while simultaneously inform next of kin and health personnel of these wishes.

> *Everyone should create an aging plan that considers what kind of aging one wishes (living situation, use of technological tools and data). The aging plan should be developed at an early point in life but should also include an option for making changes along the way.*

Technology can be positive and facilitate for increased autonomy, but in order to strengthen and maintain intergrity, the use should be voluntary and provide an option for individualized customization. GPS was highlighted as a liberating technology. Several participants felt the diffusion of GPS technology to people with dementia was too low and highlighted the importance of everyone having equal access to technology resources, regardless of municipality.

> *All persons with dementia, their next of kin and health personnel must know about the opportunities of the GPS technology. This improves safety and contributes to a greater freedom of mobility for people with dementia. Simultaneously, the technology can save large societal costs by reducing the number of search parties. This can be realized through a GPS-promoting campaign on the municipalities or from a higher level.*

> *Politicians should explore the possibility for standardizing procurement competence when acquiring welfare technology and ensure collective guidelines for reducing discrepancies in municpal offerings.*

The participants considered the robot dog described in the scenario as a positive technology, given that it is merely intended for socialization and the user enjoys it. However, it was emphasized that social technology should not replace human contact but rather function as a supplement.

INCLUSION

Several participants were very positive to the concept of generation villages. A place where one can better utilize available resources while creating a cohesive community will be important going forward. People with dementia and the elderly should not be isolated in institutions but rather be included in society.

> *Building generation villages. The authorities must take initiative and create funding schemes. Local government must have projects, one can apply to, for example, the house bank for loans. They implement and contol the composition and incentives for living there (e.g. guaranteed spot in the kindergarten, good loan offers, sufficient public transportation and health houses with gym facilities).*

> *In order to ensure autonomy and dignity for as long as possible, we must increase competences in facilitating for a dementia friendly society. Training retail personnel, assistance with public transportation. Universal development must be implemented in the planning of smart cities.*

PRIVACY

When potentially invading technologies enter our homes, we need independent guidance and help with choosing the right technology and settings. The participants were concerned with how to facilitate for sound and well-informed decision-making.

> *The Ministry of Local Government and Modernization and the Ministry of Health and Care Services must ensure that all municipalities have their own welfare technology agent (possibly connected to the municipalities' data protection officers), that can help guiding those with additional needs for assistance. This person must possess knowledge about data streams, dementia, technology, law and ethics. This must become a right, related to needs/degree of cognitive impairment such as «memory teams.»*
>
> *There is a need for an increased focus on digital competence among next of kin and health personnel. Courses for next of kin should be updated with information about digital tools. Technology must be included in health classes at an early stage and we need earmarked funds for further education of health personnel.*

SCENARIO 3 – «SAFE SURROUNDINGS»

In scenario 3, there is a systematic nationwide focus on early diagnosing and prevention through the dementia program. The local government ensures continuous follow-up and data collection through new technology. Several of the participants were positive to increased government control of municipal suppliers to create equality in the offerings and standardized systems.

SCREENING AND PREVENTION

The participants were split in their opinions about the screening program and much of the discussion revolved around this. Some meant that if the screening gave accurate results, everyone should be strongly encouraged to participate. Today, it is not uncommon that people wait long before receiving a diagnosis, which tears on family and network relations while the disease gets progressively worse. Thus, the screening would be a good tool for establishing early contact with people susceptible to developing dementia. This could also improve planning in the health sector and provide researchers with data needed to get closer to solving the dementia mystery.

Others meant these screening programs are rather worrisome. Getting to know that one is likely to develop dementia is something that could, even with good follow-up, impair quality of life significantly. Others commented that not wanting to participate in the screening could be perceived very negatively. Such pressure would impede autonomy. To maintain autonomy, each person should be able to decide whether they want to know their risk for developing dementia or not. One should also be able to control who, in addition to oneself, is able to access to this information.

Additional worries were expressed regarding overtreatment and false positive results. It was suggested that the public health perspective should focus on prevention of dementia by encouraging a healthy diet, an active lifestyle and exercising the mind.

THE RIGHT OF RESERVATION

The groups discussed the right to reserve oneself from technology and the right to not be analyzed in the future. Some commented that today's technology is mainly used for health personnel and that patient mastering is a positive additional effect. It was also stressed that each technology must be evaluated individually and should only be used if it contributes to improve the service quality for the patient. Others believed that all should accept technology and data collection in the health- and care sector in order to utilize resources in the best possible way and stimulate new research.

SAFETY FOR WHO?

The participants liked how the technology could contribute to making the home feel just as safe as a nursing home. Simultaneously, there are normally multiple people in a household with different wishes and needs. It is not certain that the next of kin wants to be analyzed and monitored. Participants noted that safety for the patient and safety for the next of kin are not necessarily in unison and that all needs should be addressed individually. Others in the household should be included in the use and selection of sensors and technology in the home.