

A Better Life for Elderly Sick People

MAJOR IMPROVEMENTS OVER A SHORT TIME



Swedish Association
of Local Authorities
and Regions



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Foreword

“I can age in comfort and autonomy with access to good health and social care.”

This vision was formulated four years ago. We’re not quite there yet, but we’re on our way.

- Nearly 20,000 elderly people are no longer treated with inappropriate medication.
- Fewer and less severe pressure sores among sick elderly in both municipal and county healthcare institutions.
- Risk of malnutrition detected and remedied – about 25,000 risk assessments every month.
- People with dementia get the right care – anxiety and aggressiveness decreased.

These are just a few of the improvements that have been seen in elderly care since 2010, when the first agreement on coordinated health and social care was entered between the Swedish government and the Association of Local Authorities and Regions (SKL).

These improvements were achieved through a persistent and systematic change management process, implemented by managers and employees working in health and social care for the elderly in all Swedish municipalities and counties, and coordinated and supported by a team at SKL. This report presents the results of this process and the path to these results.

It is possible to implement major improvements over a short period of time.

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Problems – then and now

Then

Good medical results and probably the best elderly care in the world, but still poor continuity and many contacts with health and social care that just weren't connecting.

At the start of the initiative in 2010, interviews were conducted with nearly 300 sick elderly people who had a large consumption of health and social care. They spoke about a system in which it was easier to call for an ambulance and go to the hospital than to get an appointment at the medical center. Many did not have a regular healthcare provider for their primary care. Every fifth sick elderly person admitted to the hospital was re-admitted within 30 days.

The use of inappropriate medication was high, as was the number of drugs that were prescribed simultaneously. Staff worked hard but out of sync and without an awareness of the total picture and the results of all of their activities. Opportunities for following national guidelines and applying new knowledge in the area of dementia were lacking. Preventative efforts were either fragmented and unsystematic or nonexistent. A coordinated outpatient care plan was not the norm; nor were home doctor's visits. Improvements were frequently made in temporary projects, which were often terminated when the money ran out. Death came as a surprise and was not something that was discussed.

For quite some time, inadequate cooperation on many levels has been a problem. Municipal, county and primary care institutions have not had any natural common arenas. The first time executive managers from both municipal and county institutions met in the same room to discuss common challenges was in the spring of 2011. This can be said to be the start of the quiet revolution that has characterized health and social care in recent years.



Now

Today, five years later, health and social care staff are working with new standardized, common and evidence-based approaches. Systematic appraisals and risk assessments have led to the implementation of preventative measures and it is now possible to follow key results in real time. Better monitoring of pressure sores, malnutrition and falls has led to fewer serious pressure sores. Malnutrition has decreased and falls are increasingly prevented.

Quality registries have become commonplace in municipal health and social care institutions. Access to data from health and social care has made it clear that there is an inequality in care. Where one lives and receives care plays a major role. Women and men are not always treated equally. For instance, women who seek help for suspected dementia are on average older and have lower cognitive skills than men.

Improvement initiatives implemented in regular operations provide results. Drug therapy has clearly improved. Hypnotics have largely been replaced with physical activity during the day and a nutritious evening meal. Good nursing care has replaced neuroleptics in the care of dementia. Although

at a modest level as of yet, more people with dementia are being diagnosed early and correctly. Many are phoned at home after being discharged from the hospital. Questions and uncertainties can be cleared up and any problems addressed. Pain estimates increase the chances of pain treatment and a dignified end of life. Cooperation and continuity are still not optimal at all times and in all places.

But it has never been better than it is now!

TABLE 2. Transition from then to now

	Then	Now
Approach		
Evidence-based	We do what we've always done.	We work according to the best available knowledge.
Law and order	Ad hoc - we take things as they come.	Structured and systematic.
A step ahead	Reactive - we'll deal with it when it happens.	Proactive and preventative.
From believing to knowing	Belief. Work on a gut feeling.	Measure and follow up. A handle on the situation. Quality registries. Indicators. Open comparisons.
Culture		
From organization to person	Organizational focus.	Elder's focus, individual's needs.
Talking about to talking with – seniors and relatives as active co-creators	The elder as an object.	The elder as a subject.
Creating value	What is your diagnosis? Follow a care program.	What is your situation? What is important to you?
Seeing the whole person	Assembly line	Big picture



The Better Life initiative

An agreement with the government

A Better Life for Elderly Sick People has been made possible through a framework agreement between SKL and the Swedish government on *Coordinated health and social care for the most severely ill elderly people*, in which annual agreements about the details were made from 2010 to 2014. Five areas have been identified for improvement.

- › Preventative approaches
- › Good care for dementia
- › Good care in the final stages of life
- › Good drug therapy
- › Coordinated health and social care

The focus of the agreement was to support municipalities and counties in developing a common, long-term and systematic change management process. The municipalities and counties that achieved the set objectives were awarded performance bonuses. Funds were allocated for development leaders, management support, quality registries and analysis work. SKL was responsible for national coordination. Experimental research activities, quality-assured welfare and mental illness also received financial support through this agreement. In total, the agreements comprised SEK 3,834.5 million. SEK 2,815 million has been paid in performance bonuses to municipalities and counties.¹

Note 1. Coordinated health and social care for the most severely ill elderly people. Follow-up of agreements between SKL and the Swedish government. Statskontoret (The Swedish Agency for Public Management) Interim Report 5.

TABLE 2. Agreement – total appropriation 2010–2014. Million SEK

Initiatives	2010	2011	2012	2013	2014	Total
Increased use of quality registries, of which:	120	120	238	316	319	1,113
Performance-based compensation	100	100	210	290	290	990
Support for the registry	19	19	27	25	28	118
SKL coordination	1	1	1	1	1	5
Performance bonuses for good use of medication	-	-	325	300	300	925
Performance bonuses for good coordinated health and social care	-	-	325	325	250	900
Support for local and regional development	68	68	193	153	123.5	605.5
Research activities surrounding the most severely ill elderly	70	70	70	-	-	210
National coordination	28	13	10	21.5	8	
Total	286	271	1,161	1,115.5	1,001	3,834.5

Source: Coordinated health and social care for the most severely ill elderly people. Follow-up of agreements between SKL and the Swedish government. Statskontoret (The Swedish Agency for Public Management) Interim Report 5.

Basic requirements were set for participation in the performance bonuses. Municipalities and county councils must have a structure for joint management and administration, prepare annual joint action plans, and have a management system in place for systematic quality initiatives.

On a large scale

When the initiative began in 2010, there was a strong desire for change and a great consensus among the leaders in municipalities and counties concerning the problems. There was evidence regarding approaches that were not applied systematically in operations and there were metrics, indicators and change concepts. The time was ripe to invest in rapid change on a large scale.

To make a difference for elderly sick people, changes must be made in the interactions between employees and the elderly. There has therefore been great focus throughout the project on care approach. Quality registries have functioned as expert support in this context and have also made it possible to follow developments in real time.

Questions such as *Who are we here for?* and *How does this create value for the person who is elderly and sick?* have been common themes in the project and are necessary for effective cooperation between professional groups and organizations.

FIGURE 1. Work on multiple levels



The initiative has been aimed at all those involved in health and social care for sick elderly people. Politicians and managers at all levels have been involved. Development leaders and analysts have provided support for the work. Many professional groups have been involved – doctors, nurses, out-patient staff, physiotherapists, occupational therapists, dieticians, pharmacists, assistance administrators, etc. And the work was carried out in cooperation not only between municipal health and social care institutions, primary care and hospitals, but also with the elders and their relatives.

Toward more equal health and social care

The Swedish system of developed local self-government offers the opportunity to find effective welfare solutions based on local conditions, needs and priorities. The downside is a risk of inequality in health and social care. The initiative has handled this fact by setting clear objectives and by, in a transparent and simple way, showing the results on the national, regional and local levels. There may be different paths to the same goal, and there is rarely one solution that fits all.

Some must go ahead and show what can be achieved. It is important that everyone strives to be a little better every day and that this can be demonstrated.

Rapid dissemination of quality registries

At the start of 2010, most municipal employees were relatively unaware of the quality registries – why they existed and how it was possible to use quality registries in the local improvement initiatives.

The dissemination of quality registries in municipal health and social care has taken place at record speed. The desire for change and the determination to move from words to action played a vital role in this, along with the stimulus of the performance bonuses.

Senior alert, the Swedish Register of Palliative Care (SRPC), Swedish Dementia Registry (SveDem), Swedish Registry for Behavioral and Psychological Symptoms of Dementia (BPSD) and the Swedish National Quality Registry of Ulcer Treatment (RiksSår) are the registries used in the initiative. All offer the opportunity to monitor developments in real time on different levels, and also serve as support for the care team to work effectively based on the best available knowledge.

Work began in 2010 with the SRPC and Senior alert. It continued with the SveDem and BPSD registries in 2012, with RiksSår added in 2014.

Senior alert

Provides support for a structured and systematic preventative approach. Risk assessments for falls, pressure sores, malnutrition, oral health and bladder dysfunction are conducted simultaneously using standardized risk assessment tools. If a risk is detected, the team investigates the causes, plans preventative measures, and then follows up on the measures and their effect. For the preventative work to be effective, each organization must follow up on their results, analyze them, and make improvements where needed.

Dissemination was rapid, with 24 employed coaches from the registry visiting municipal and county institutions in 2010/2011.

FIGURE 2. Dissemination of Senior alert 2009–2014

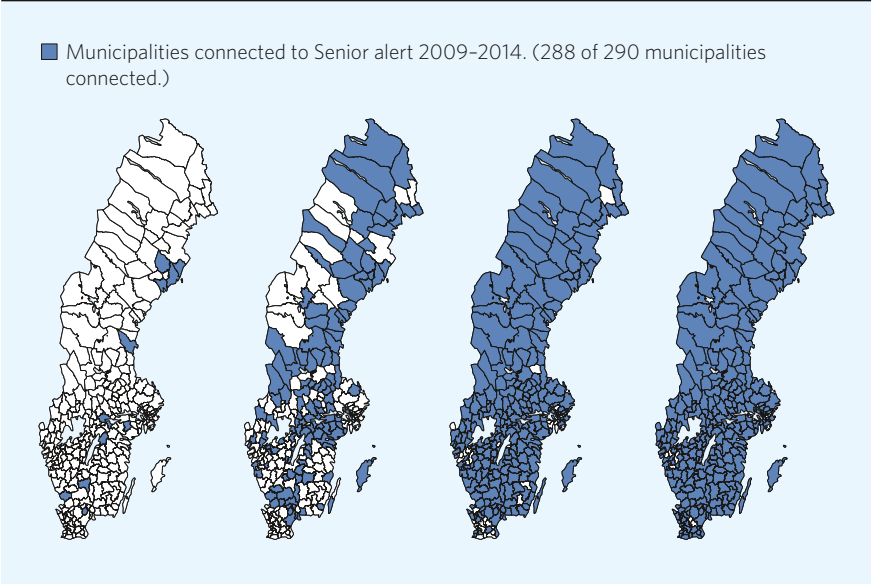
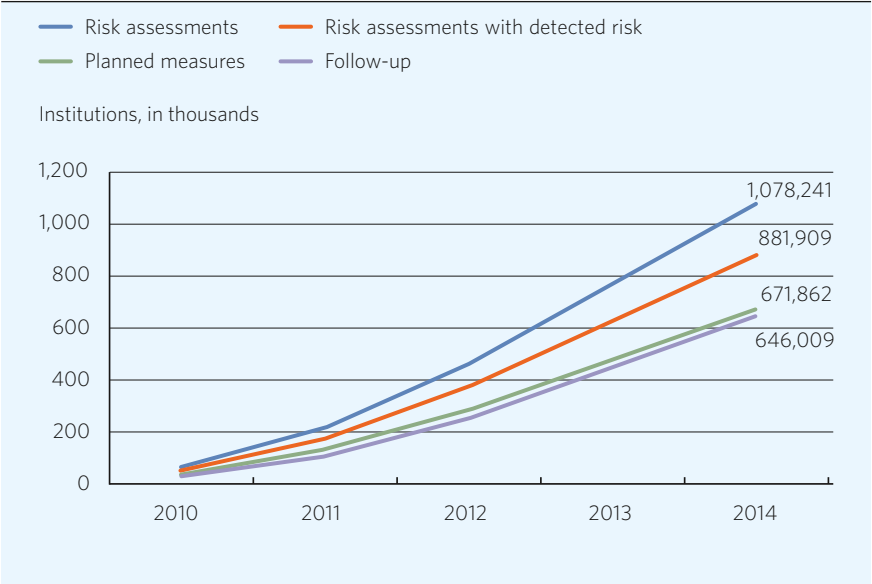


FIGURE 3. Risk assessments, measures and cumulative follow-up, all institutions, nationwide



Approximately 12,000 institutions in 288 of 290 municipalities and all county councils/regions are connected to Senior alert. 85 percent are public and 15 percent are private.

Swedish Register of Palliative Care (SRPC)

Care providers document in the registry how the care was for a person in their final stages of life. The objective is to improve care in the final stages of life regardless of diagnosis and who provides the care. Analysis and reflection on the team's results form the basis of the improvements. The registry works according to seven objectives based on the dying person's perspective.

I ...

- › and my relatives are informed of my situation
- › am relieved of pain and other troublesome symptoms
- › am prescribed medication as needed
- › receive good nursing care based on my needs
- › am cared for where I want to die
- › do not need to die alone
- › know that my loved ones will be given support

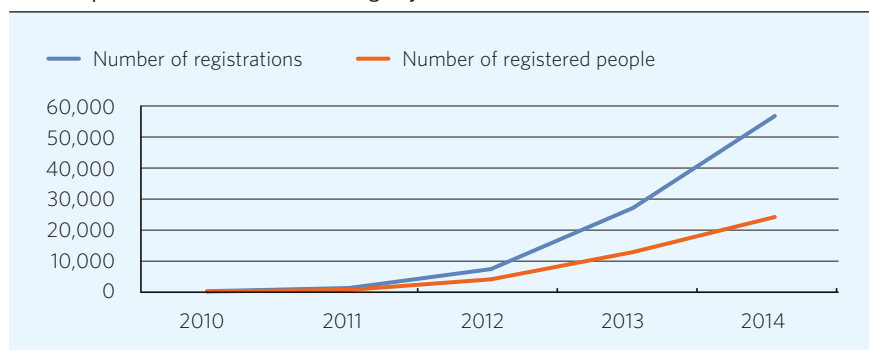
The Swedish Register of Palliative Care, which started in 2005, has employed field workers to support implementation throughout the country. The extent of coverage has increased from 25 percent in 2009 to 67 percent in 2014.

SveDem

The objective is to support approaches in accordance with national guidelines for the care of dementia. Data regarding investigation, treatment and follow-up are collected to improve opportunities for early detection and proper investigation and diagnosis, which is an important prerequisite for people with dementia receiving the right support to live independently as long as possible.

Dissemination in primary care has been rapid. Of the country's approximately 1,200 medical centers, participation has increased from 82 to 880 over the years between 2011 and 2014. Data is now registered on a total of approximately 47,000 investigations with initial registrations and 31,000 follow-ups.

FIGURE 4. Dissemination of the BPSD registry



BPSD registry

Behavioral and psychological symptoms of dementia, BPSD, affect about 90 percent of all people living with dementia. These symptoms include aggression, anxiety, apathy, hallucinations and sleep disorders. They cause great suffering, particularly for the person with dementia, but also for their relatives and healthcare staff. The purpose of the BPSD registry is to, through personalized measures, reduce BPSD and the suffering they cause, thereby increasing the quality of life for the person with dementia.

To measure the presence and severity of BPSD, the NPI scale is used.² Checklists are available to assist in the analysis of underlying causes and, after analysis, team-based care measures are implemented. At follow-up, BPSD are measured to see if they have changed.

The BPSD registry was disseminated in record time. From its start in 2010 to 2014, 23,000 people with dementia received 53,000 assessments. 4,250 institutions in 280 municipalities are now participating in the work.

RiksSår

For people with chronic ulcers that do not heal within six weeks. These include leg ulcers, pressure sores or foot ulcers in diabetics. The purpose is to use the registry to help make an accurate diagnosis in order to provide the best treatment and thereby help the sore to heal faster.

The Swedish National Quality Registry of Ulcer Treatment, RiksSår, came into the initiative in 2014 and is still in an early stage of dissemination. A total of 2,600 ulcers have so far been registered. This work was not included in the performance bonus program.

Note 2. Neuropsychiatric Inventory Scale, which measures twelve different symptoms.



EXAMPLE: Right care turned her life around

Elsa has had an ulcer on her collarbone for over a year. She notices that the home care staff is disgusted when the ulcer leaks and smells bad. Although the bandage over the ulcer is changed every day and the doctor prescribes antibiotics, it won't heal. Elsa quietly believes that it is cancer, and that thought preys on her mind.

Elsa's ulcer is not cancer – it is a pressure sore. With diagnosis, personalized treatment and continuity, the pressure sore would have healed in four months. Elsa's life took a new turn when she got the right care and could leave all the worry behind.

Development leaders – a motor for change

Implementing a change requires support and resources in the form of development expertise, analytical skills and financial calculations. Development leaders and analysis work have filled this role. There have been several development leaders per county during the project.

Researchers at Karolinska Institutet specifically studied the development leaders' importance for the rapid dissemination of the quality registries. Their time and provision of support for the organizations, along with knowledge of change management, registries and methods, was very significant to the realization of all the plans. The development leaders also arranged training courses and exchanged experience regionally, and helped present the results in an understandable and appealing way.

Key leadership

For the employees to be able to work according to new evidence, they need support from their managers. The managers are also important for ensuring that new approaches are introduced in all organizations and operations. The *Ledningskraft* (Empowering Change) program came into being in 2012 and has functioned as a source of power in health and social care. Through *Ledningskraft*, manager teams from municipalities, primary care and hospitals met in national and regional forums to move from words to action. All counties in Sweden participated with one or more teams, a total of 300 people. The importance of this cannot be overstated. The forums were characterized by hard work, and gave the participants not only a common understanding of what must be done, but also the muscles to actually do the job. The starting point was the politically established action plans formulated by each county. Unlike many other plans, they have also largely been implemented.

More information about the program is available in the report *Ledningskraft – Designing managerial support in large-scale change management*.

Involved and committed seniors

Commitment is also needed from those health and social care is there for – sick elderly people and their relatives – yet also from healthy seniors who want reassurance that the system will work when the day comes that they need it. A Better Life for Elderly Sick People cooperated with the major pensioner organizations and also strived in all contexts to have a senior involved.



CHAPTER 3

Why it was successful

Concentrated efforts in which municipalities and county councils throughout the country determinedly work toward the same goals proved to be successful. A high tempo and large-scale implementation contributed.

Responsibility for the change management process remained in the regular line organization throughout. Project models have only been used to develop new concepts in the areas lacking in evidence-based findings.

Courage, will, stubbornness and perseverance among the health and social care managers and staff were key ingredients. Clear goals, effective tools, and investment assistance in the form of performance bonuses did their part.

Following up results at the highest level has proven to be a key success factor. What no one asks for never gets done.

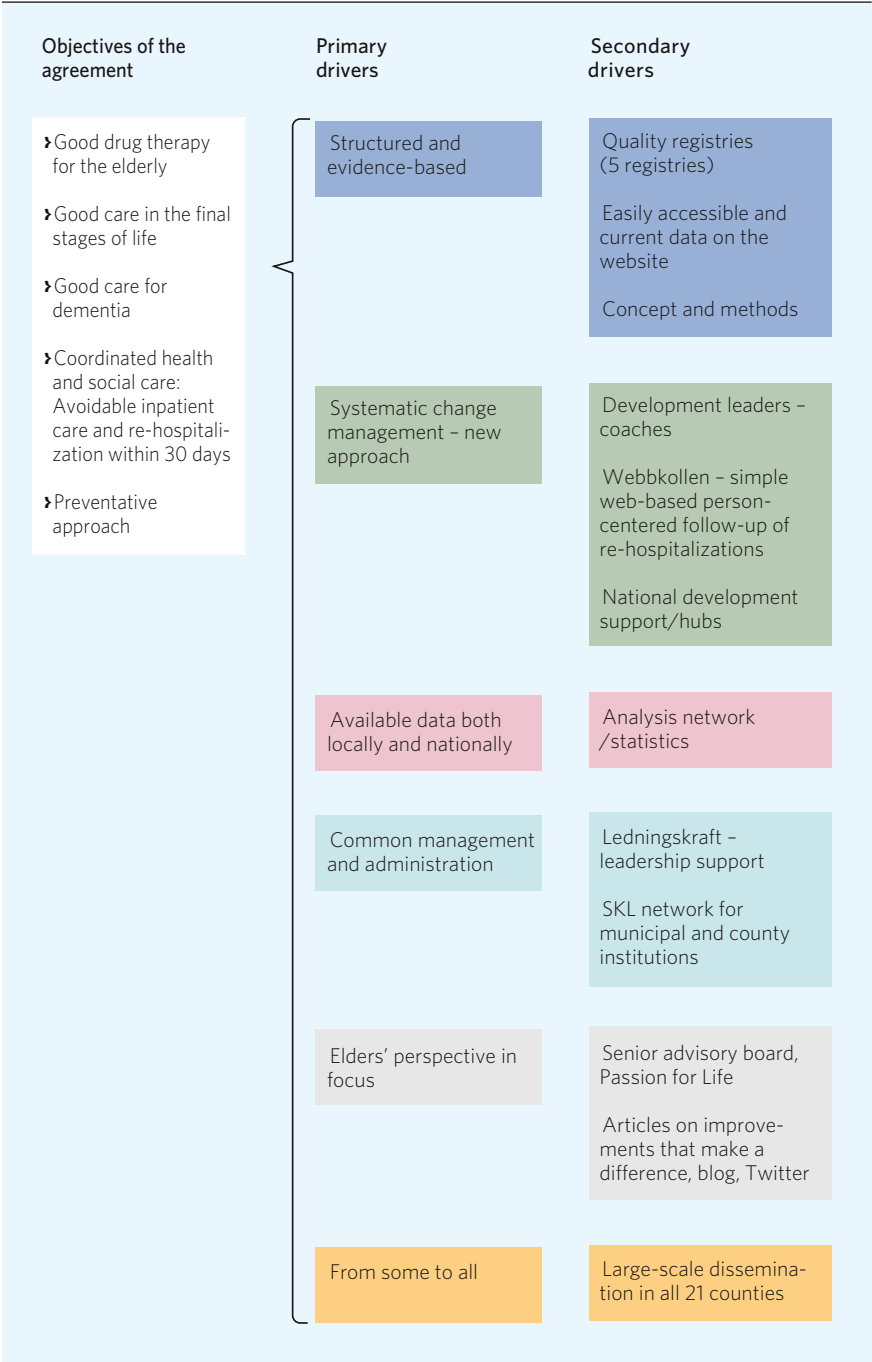
The quality registries and a quality portal where results could be monitored in real time has been crucial to the results. Everyday accounts from health and social care have supplemented curves and indicators and helped create pressure for change. The desire to learn and improve emerges when the team reflects on their results together.

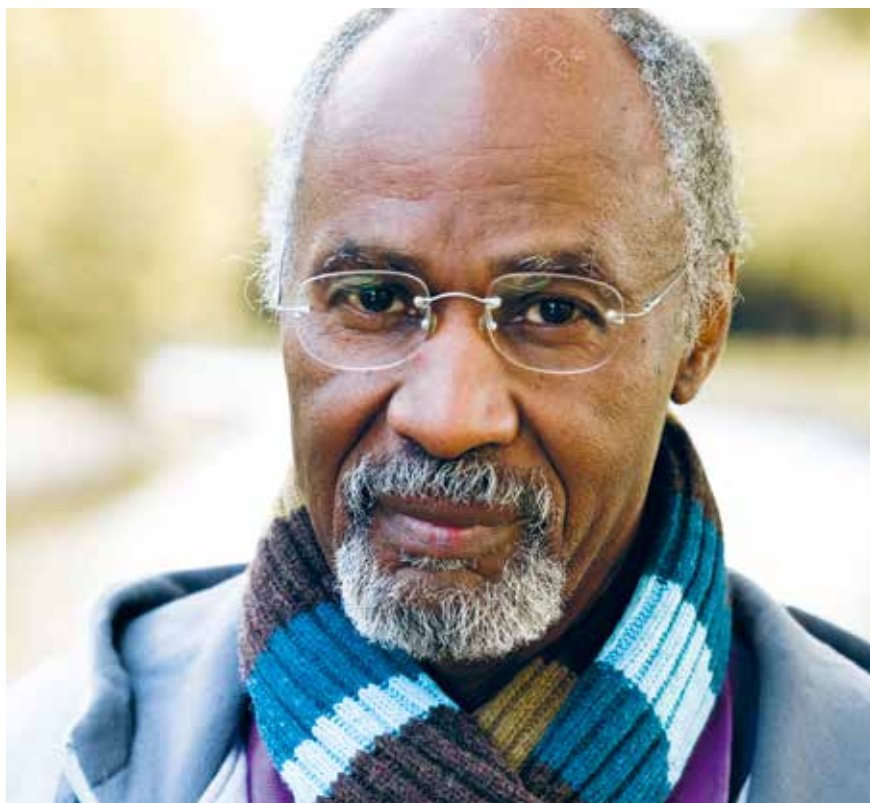
A cultural change is underway, which is all about shifting perspective from the organization to the person. Respecting the individual and finding ways to meet the needs, wishes and dreams of the sick elderly is about more than correctly treating a number of diagnoses according to applicable care programs and checklists.

Acting in a new way of thinking instead of thinking your way into a new way of acting was a conscious strategy. Testing and then implementing a new approach in an institution can often be done in three months. Cultural change takes time, but behavioral change can go quickly.

Planning was done with the help of *back-casting*. Instead of planning one step at a time in the usual way, a question was posed: What do we need to do to ensure that a goal is reached at a certain time?

FIGURE 5. Driver diagram, the link between objectives and improvement initiatives





In a *driver diagram*, several different perspectives have been identified as primary driving forces in achieving the goals of the initiative. When secondary drivers affecting primary drivers are identified, a pattern emerges of how all parallel activities contribute to the big picture. Each activity was tested: In what way will this activity contribute to the goals of the initiative? In complex systems, unexpected effects often arise. There must always be a readiness to reconsider and make adjustments.

“You have to decide. Then good things will happen, often in a short period of time.”



CHAPTER 4

Objectives, metrics and results

The initiative covered five areas for performance bonuses: preventative approach, good care for dementia, good care in the final stages of life, good drug treatment, and coordinated health and social care, with objectives connected to each. Each year, the requirements have been tightened.

Preventative approaches

Preventing people from being injured and maintaining good health are on their way to becoming commonplace in eldercare. Quality registry Senior alert provides support for a new, team-based approach.

In Senior alert, persons aged 65 or more who are receiving health or social care are offered a risk assessment for falls, malnutrition, pressure sores, oral health, ulcers and incontinence. If the risk is overt, at least one measure is implemented immediately; at follow-up, measures can be further refined.

Everything is connected. Poor oral health can lead to malnutrition. A malnourished person is more susceptible to falls and developing ulcers. A person who falls and becomes bedridden has an increased risk of developing pressure sores. There is also an aggravated risk for care-related infections for a person that is malnourished or has pressure ulcers.

Employees in different professional groups work on a daily basis with preventative measures. The areas cut across the boundaries between medical specialties regardless of principal. A national and shared database is available through Senior alert. It provides a basis for which to evaluate and compare the work of different institutions on preventative health.

In 2013, a collaboration was initiated with the RiksSår quality registry – from prevention to treatment and healing.

No one should have to be malnourished

The most common measures to prevent malnutrition are extra snacks, nutritional drinks, and reducing night fasting to a maximum of 11 hours. Extra nutritional and calorie-rich snacks are preventative measures that have become commonplace in many institutions.



At Åsliden nursing home in Skåne, rusks were replaced with smoothies in elegant glasses.

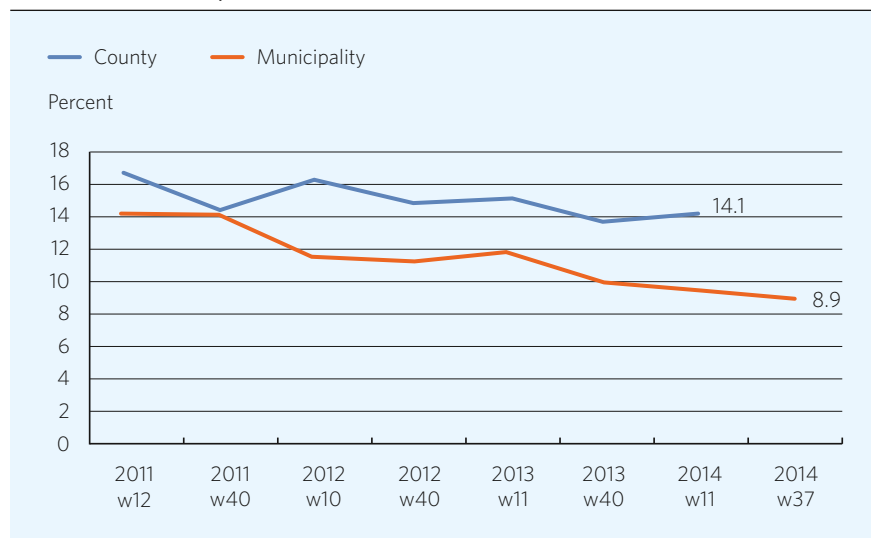
Results are now showing a smaller percentage of *weight loss of more than 5 percent* in both municipal and county institutions. In municipalities, from 14.3 percent in 2011 to 13.4 percent in 2014. In county councils, the weight loss percentage has gone from 5.1 percent to 4.6 percent. This means that malnutrition has been able to be prevented in several thousand elderly sick people.

The institutions that work with oral health assessments have even fewer malnourished seniors.

Zero vision for pressure sores

The incidence of pressure sores is decreasing in both municipal and county institutions. Pressure sores are also becoming milder.

FIGURE 6. Decrease in pressure sores



The percentage of stage 3 ulcers has decreased from 31.7 percent to 15.5 percent within the municipal institutions. In county institutions, stage 3 ulcers have decreased from 29.3 percent to 12.0 percent. Pressure sores of stages 3 and 4 are now about *2,500 fewer* than would be expected if the level had remained the same as in the 2010-2012 period.

EXAMPLE: Assistant nurse's story

Ines lives alone in her own apartment. She is talkative and social, but lives a rather solitary life anyway. Ines fell about five years ago and broke her femur. After that, she was very afraid that she would fall again. She had a walker that she used to walk short distances indoors. But she hadn't been outside on her own since she fell.

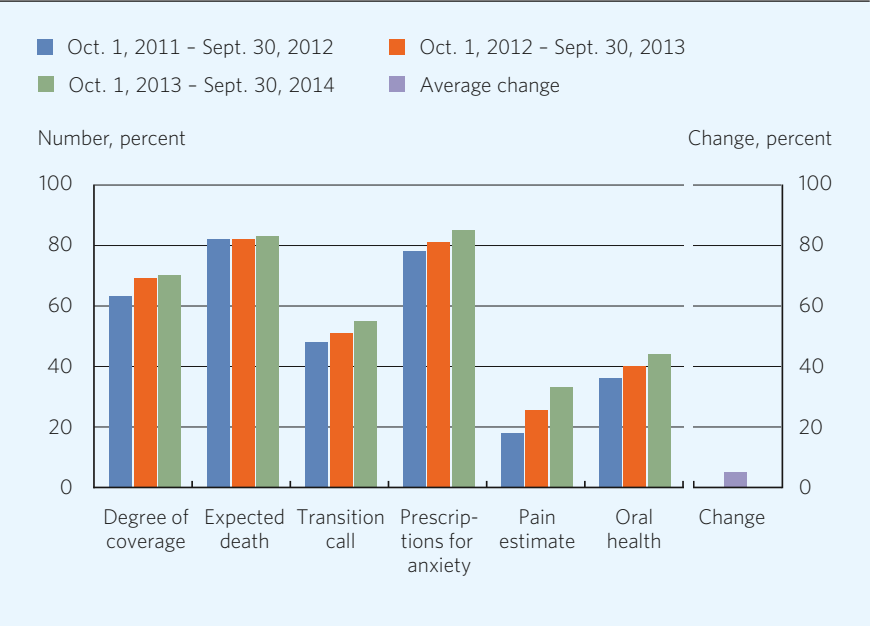
When we started to work with Senior alert and had a team meeting about Ines, we saw that the walker wasn't helping with her fear of falling. Ines was put on an exercise program in which she trained her balance, strength, etc. We also started to take short walks with the walker. Ines wanted so badly to be able to go out by herself and felt that the exercise was doing good. Just before Christmas, I met Ines with her walker out in town. Her family was coming to visit and she had decided to go out shopping for something good to go with the coffee!

Good care in the final stages of life

By recording people’s last week of life in the Swedish Register of Palliative Care, it becomes clear what is good and where there are areas for improvement.

The objective of the agreement was to improve four indicators that have been particularly prioritized in national guidelines. These were to increase the prescription of drugs for anxiety, perform oral health assessments, make systematic pain estimates, improve information and make “transition” calls. In all areas, improvements have been seen each year on a national level.

FIGURE 7. Improved care in the final stages of life, nationwide



EXAMPLE: Senior physician’s story

90 percent of dying patients at our facility have the opportunity to receive relief from pain, anxiety, nausea, and shortness of breath. In the rest of Sweden, only 50 percent have as-needed prescription for nausea. The most obvious change has been for those with heart and lung diseases, more of whom now find relief for their dyspnea. A large percentage previously died alone. We’ve become better at talking to relatives and inviting them to stay the night – we’ve bought extra beds. Without the palliative registry, we wouldn’t have seen the deficiencies in care so clearly and been able to fix them.

Good care for dementia

Early detection, investigation and diagnosis are important in dementia. The course of the illness in this incurable disease can be eased and good care can be provided to more people while maintaining their autonomy. The drug treatment provided is generally most effective if it is begun early. With the support of the municipal institutions, people suffering from dementia can lead functional lives.

Good municipal nursing care can replace antipsychotics. In both dementia registries, the use of these drugs is decreasing. The risk of falls and fall injuries are decreasing simultaneously.

Better investigation of dementia

In primary care, 46 percent of those registered in SveDem underwent a basal dementia investigation in 2011. In 2014, this figure rose to 66 percent. The patient group is becoming more visible, more are investigated, the quality of the investigation and follow-up are increasing, and more people are likely to be diagnosed earlier in the course of the illness.

EXAMPLE: District nurse's story

We now have a structure for investigation and follow-up of our dementia patients. Our follow-ups have become better and more continuous. Supported by SveDem, we ask patients more relevant questions, and are able to better meet their needs.

Relief of behavioral and psychological symptoms of dementia

For the 275 people who had more than 50 points on average on the NPI scale³ at initial registration, BPSD were significantly reduced: from 69 to 39 points. The most severely ill, with the most severe symptoms, have shown the greatest improvements.

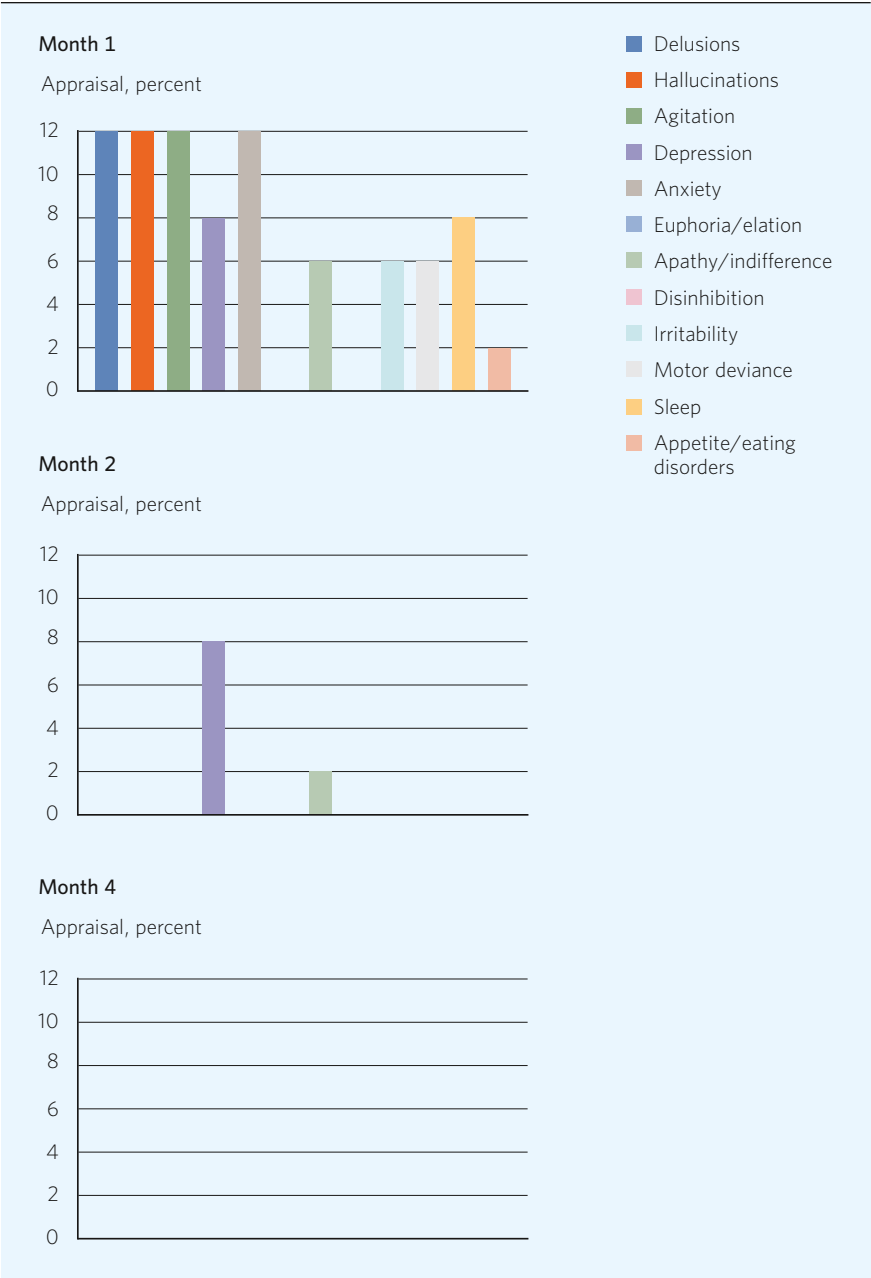
In 2014, it was possible to deduce that men have somewhat higher scores in agitation, disinhibition, motor agitation and sleep disturbances. The women, on the other hand, had higher scores in anxiety and depression. Gender distribution in the registry: women 65 percent, men 35 percent.

The diagram on the next page shows how Anna, age 68, became free from symptoms with the help of appraisals and rectification measures. This took four months. She took walks with staff and with her husband, and was encour-

Note 3. Neuropsychiatric Inventory Scale, which measures twelve different symptoms.

aged to help with daily chores. She then received aids to keep track of time and her neuroleptics could be reduced.

FIGURE 8. Symptom appraisals over time, for Anna, age 68



EXAMPLE: The relative's story

With the help of singing, massage and pain-relieving ointment, Mom became much happier and more alert, and often says that the staff is kind. She feels like a queen! I can see that the staff has really made an effort to make changes with my mother and they themselves see that they have achieved results. We relatives now feel like we are cooperating – they don't take our questions as negative criticism. This rubs off on the other residents, who have become more active and happy, and who talk more with each other without getting angry.



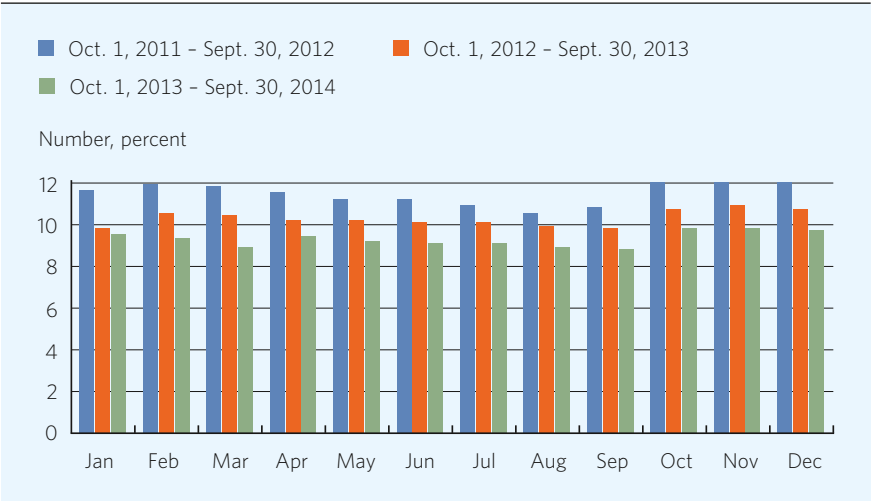
When the municipality of Kiruna started working with the BPSD registry, the number of reported incidents of threats and violence against the staff decreased by over 20 percent per quarter to 3 percent in the last quarter of 2014.

Good drug therapy for the elderly

For very many years, the question of inappropriate drug treatment in elder-care has been an issue. The knowledge has been there, but far too many elderly patients have still been prescribed inappropriate drugs. It has been difficult to effect a change. Over the years of the initiative for a better life for elderly sick people, major improvements have been made in all counties, although there are still differences both within and between counties. The counties that have had the greatest usage of inappropriate medications have improved most, but even the best counties have reduced their use of inappropriate drugs for elderly patients.

Roughly 20,000 fewer seniors use inappropriate medications today, a decrease of 23 percent in three years.

FIGURE 9. Decrease in inappropriate medication, >age 75, nationwide



Source: kvalitetsportal.se.

EXAMPLE: Pharmacist's story

I really like working with medication reviews. I remember one patient in particular, Ferenc. His daughter told me that he had become confused, started losing weight and had fallen several times and hurt himself quite badly. He now only wanted to lie in bed and was unsure if his legs would hold him. When he and I, along with his nurse, doctor and daughter, went through his medication, we could see that several of the drugs he was taking caused dry mouth and confusion. The doctor changed his medication, and now both the confusion and the dry mouth are gone. He is up and moving around again, eating with a good appetite and feeling much better.

Coordinated health and social care

The difficulties of offering sick elders coordinated health and social care is well known and well documented. The problem is not unique for Sweden, but exists across the globe in all healthcare systems.

Deficiencies in outpatient care or in municipal institutions increases the risk of admission to inpatient care. Every fifth sick elder over age 65 who is treated in the hospital will be re-hospitalized, unscheduled, within 30 days.

Over the years of the Better Life initiative, no major changes have been measured on a national scale.

Many factors influence the risk of re-hospitalization and there is no single measure that could easily lead to a better result. For individuals and for selected groups, it is possible to implement measures allowing the sick elder to be cared for in his or her own home without needing to go in to the hospital.

Impacting an entire system, however, requires additional measures, and efforts have not come this far yet. This is likely due to the extensive lack of knowledge about what changes should be disseminated on a large scale. Such knowledge is being built up with the support of tests and research activities conducted during the period.

This involves preventative measures, care planning, continuity and availability of primary care, improved information and follow-up to ensure that the information was really understood. Small changes, such as a telephone number to an eldercare nurse in primary care, can contribute to security in daily life.

Care at home instead of at the hospital

Local healthcare in west Skaraborg (Lidköping, Götene, Skara, Grästorp, Vara and Essunga) started in 2001 with the aim of strengthening collaboration between primary care, hospitals and municipal care to ensure the patient effective and safe care. The initiative includes developing home care in new forms. Today, there are three care models that work closely together: the local care team, the mobile home care physician, and the mobile palliative team. The results have been positive. Sick elders can be cared for at home and feel secure thanks to the continuity in care relationships. Admissions to the hospital and visits to the emergency room have decreased in the group. The employees are involved and committed and are satisfied with their jobs. Financial calculations have shown that this approach is cost-effective. The model is now being spread throughout Västra Götaland County and parts of Skåne.

Mobile teams with different focus areas are also in place in Ljungby, Uppsala, Sörmland and Motala.



EXAMPLE: Ward director's story

When elderly patients at the hospital are released, things have to go well. Otherwise there is a great risk that they will end up in the hospital again very soon. We work to ensure “safe and secure homecomings.” An example of this is Göte, age 93. Göte was admitted for dizziness, and absolutely did not want to go to his own home, but instead wanted to go to a nursing home.

Somewhat reluctantly, he finally agreed to a safe and secure homecoming – but only to wait until he could come into a special care facility.

As always when someone arrives back home after discharge, Göte was met in the doorway. We make sure that there is food and medicine at home, and the right tools and aids are there so that Göte could get around. We called the occupational therapist, who came later that day. After each visit, the date of the next appointment is decided. Some need more visits, others less. The safe and secure homecoming team reports to the home care team, and phases out as the home care team phases in. This safe and secure homecoming takes seven days on average. Göte needed a bit longer, 15 days. Then he felt safe at home and no longer wanted to move anywhere. And he didn't need to go to the hospital either.

Better quality and security at a lower cost

Evaluations and financial analyses indicate that both the new safe and secure homecoming approach and home healthcare in new forms mean lower costs, higher quality and greater safety and comfort for the elders. It also reduces re-admissions and emergency room visits.

The municipality of Ronneby was the first to introduce safe and secure homecoming, launching the program in April 2012. Since this time, about 25 other municipalities have introduced this approach. More are on their way.

Ask the elders – Webbollen

It is important that discharge and arrival back home from the hospital go as smoothly and comfortably as possible. Webbollen is an interview tool for determining how the elderly patients feel about their care.

As of December 2014, about 25,000 sick elders had been interviewed in their homes or upon re-admission to the hospital. The calls are very much appreciated. It is not only possible to immediately solve problems, but most importantly, the aggregate data creates an overview of how well the local healthcare system meets the needs of its sick elderly. The results can form the basis for local and regional improvement initiatives. National results are



“How are things going?”

openly presented on webbkollen.com. Special authorization is needed to make local and regional analyses.

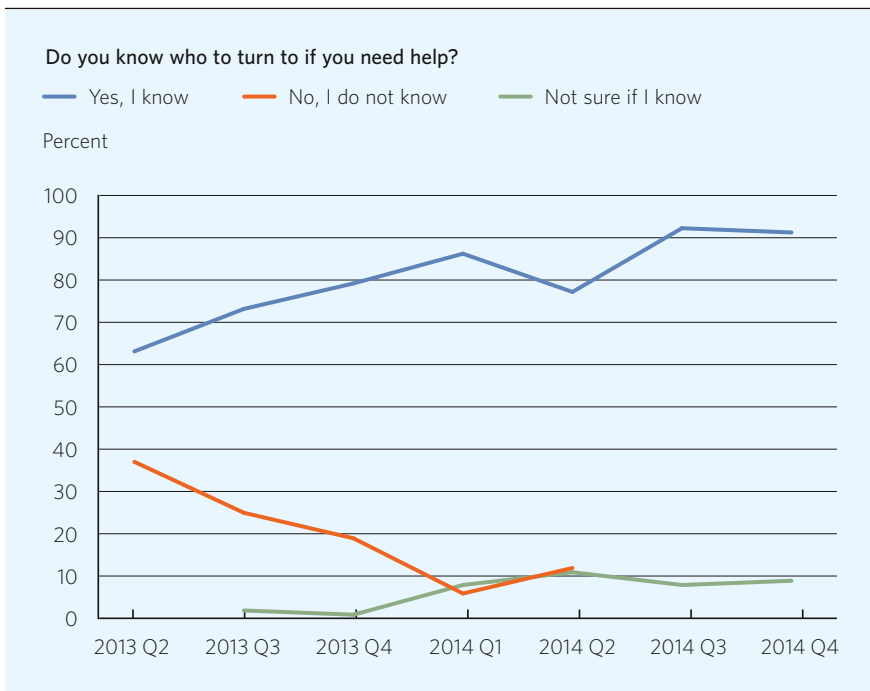
Results from Webbkollen

A common response when an elder is asked what is important to them is: “I want to feel safe and be able to take care of myself.”

83 percent of elders who have recently been discharged from the hospital feel safe. That is a good result. But why do 17 percent, 576 people, not feel safe?

Most of the requests relate to the medical centers. Insecurities have been voiced surrounding contacts with doctors and sometimes home care staff, but never in regard to nurses. On the contrary, several patients have indicated that this relationship works well and creates security.

FIGURE 10. Results from Webbkollen in Kalmar

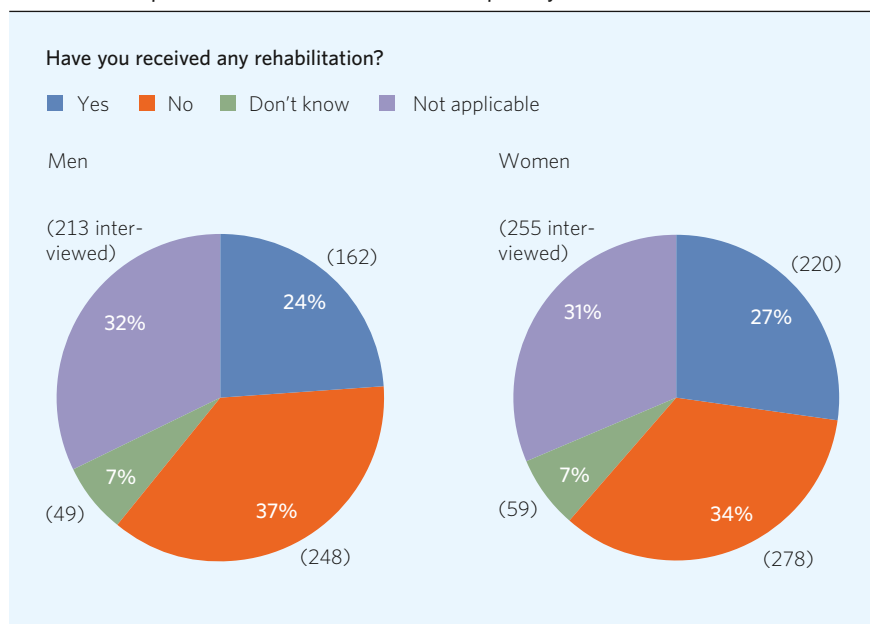


When the decisions have been made to implement a change, new approaches can be introduced quickly – provided that those involved have truly decided.

Comments from elders

- › Suddenly, I was just going to be sent home.
- › Don't know who is responsible. Think that it's too long to scheduled checkups.
- › Friendly treatment. Factual information.
- › Feels like my doctor is tired of me, doesn't listen to my situation.
- › The hospital care is good, but it's hard to get in to my medical center. There are no permanent doctors.

FIGURE 11. Comparisons between men and women in primary care



Rehabilitation in outpatient care is an area for improvement.

“Cultural change takes time, but behavioral change can go quickly.”



CHAPTER 5

Instructive approaches, major training initiatives and common theme

From 2011 to 2014, a large number of training courses have been carried out, both by the counties and the various quality registries, and via SKL's work with mental illness. The development leaders across Sweden have been a powerful and driven resource for learning, both through their own efforts and by arranging sought-after courses.

They instructed in the art of implementing transition calls, how to work to relieve anxiety in people with dementia, how to make an oral health assessment, and how to identify and approach individuals at risk for suicide, to name just a few. It is estimated that at least 60,000 employees have undergone training in some form.

Outpatient staff in particular have become more professional and developed in their professional capacity. In one example, outpatient staff in 274 municipalities completed a two-day training course through the BPSD registry.

By measuring, seeing areas for improvement, testing new approaches, and following up on the results, the work becomes a continuous learning process.

“After training, I got a completely different perspective on how I could use the registry. So far we’ve been using it mostly for registration, but we’ll be changing that.”

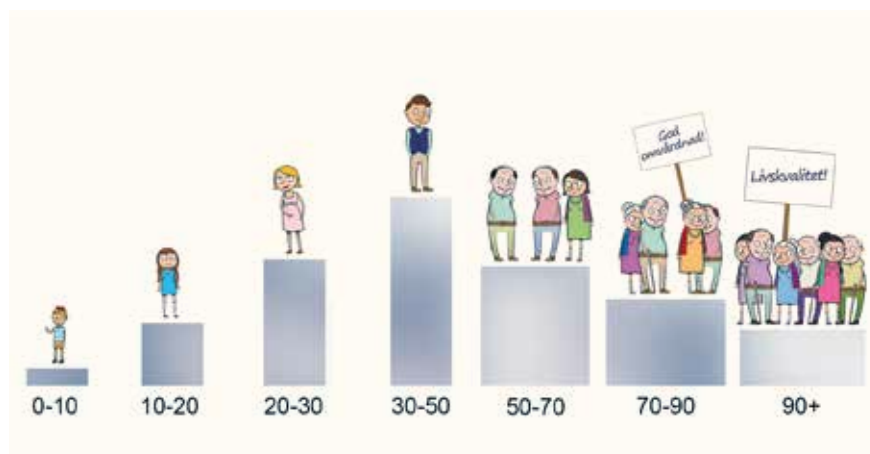
The common theme

What creates value for the person who is old and sick, and why do we come to work?

These questions have been a common theme throughout the initiative and are significant to creating a common understanding of the problems. This is crucial to getting the cooperation between different professional groups and organizations to work.

Communication in the initiative has been characterized by openness, support, transparency and a focus on results. Measure and tell. All the time in different ways, in different channels, to different target groups. Focus on who all this work will make a difference to. Clearly show the development in figures





“Good outpatient care.” “Quality of life.” More and more people are getting older and have expectations of an autonomous life.

and with real-life stories, often powerful ones. Head, heart and hands are all needed to bring about change.

Forums and meetings in small and large groups with all key target groups was the main ingredient, and were carried out on different occasions with everything from 10 to 800 participants. Short debriefings online or by telephone, for personal but travel-free contact, have been offered continuously. Support materials, news, discussion, information, results and services have been available on the website and functioned as a hub. Everyone in the SKL team Tweeted and communicated this way. At an early stage, it was decided to constantly reiterate why this is so important. To not tire, but to hold on and persevere. In order to demonstrate the value of improving their organizations and the importance of the initiative, in complex images with more feeling, videos were used in various stages. One of these videos, *Margareta’s Way*, has won two international awards.

The personal encounter was of great significance to the dissemination, and participation in different events throughout the country has been prioritized. In addition to this, articles, discussions, interviews, and availability have contributed to generating interest in the issue.

SKL’s member network and contacts have been crucial to communication. Having access to a web-based platform for communication and document management has made it possible to quickly reach out with important information and support.



Obstacles to improvements

IT support

The criticism voiced by municipal and county institutions has almost exclusively dealt with the increase in administrative work. At the start of the initiative, there were expectations that the integration between medical records and registries could relatively quickly reduce administration and double-work. This work has been full of obstacles and difficulties despite intensive efforts. As yet, no quick solution is in sight.

Deficiencies in IT support for information transfer between hospitals, primary care and eldercare is also a major issue. The National Patient Overview (NPÖ) has not yet met expectations of being able to easily share important information between different care providers.

Information on recommended medications for the patient is currently scattered over different lists at different healthcare institutions and pharmacies. Access to the information in the lists is controlled by different authorities and legislation. This means that each stakeholder in the value chain has access to their own piece of the puzzle, but that no one can see the whole picture – not even the patients themselves. The purpose of a coordinated list of medication, National Prescription Database (NOD), is to create a comprehensive picture, thereby facilitating safe use of medications.

Getting IT support worked out is high up on the wish list!

Legislation

When organizations begin to monitor their results and use these to improve operations, it can lead to legal issues. There is also a natural conflict between privacy and the desire of the healthcare sector to follow up on the results, which must be dealt with for maximum benefit.



Three municipalities have been criticized during this period by the Swedish Data Protection Authority for how they handled the issue of participation in quality registries for people with impaired decision-making capacity due to dementia. In autumn 2014, the law was changed, and now even people with impaired decision-making capacity can benefit from, and contribute to, quality developments in healthcare.

Budget and accounting standards

Government budgetary rules make it difficult to work with a long-term focus on economic stimulus. Because of this budget process, an agreement can never be decided until December, just before it enters into force, and granted funding must then be used during the current year. It is not possible to carry over

funding to the next fiscal year. Starting a initiative requires at least six months of planning and employee recruitment before work can start out in the organizations. Agreements need to be long-term and announced well in advance in order for the improvement process to proceed in a meaningful way.

How earned performance bonuses are distributed is a question for each principal. In the 2013 and 2014 agreements, a special passage has been introduced, stipulating that the funds are intended to be invested in future improvement efforts.

Many parallel priorities that don't fit together

There is great interest in municipal and county institutions in improving health and social care, but there are so many parallel initiatives that it can be difficult for a municipality and a county council to understand how the different initiatives are related and what conditions must be met.

There is a need for improved communication between the various agreements and also a prioritization and packaging of content so that it is comprehensible and manageable for the recipient.

Difficult to get information to private care providers

Now that there has become a greater diversity of providers in municipal and primary care, it has become necessary for principals to review how information about national efforts can also reach private healthcare providers. The chosen design does not exclude private care providers from participating in the improvement initiatives. Famna, the Swedish Association for Non-Profit Health and Social Service Providers, has participated in this from the beginning and their members are very involved in the work. The Association of Private Care Providers joined in 2012, and since then, participation from all private players has increased rapidly. Special resources have been allocated in agreements for development support via Famna and Almega.



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Further development for sick elderly

The framework of the agreements with the government concerning coordinated health and social care also included the following modules.

Mental illness

Some Australian materials, Mental Health First AID (MHFA), have been reworked for eldercare. Subsequently, 105 instructors were trained, who in turn trained 1,172 first assistants.

The Center for Evidence-Based Psychosocial Interventions at Lund University conducted a pilot study/evaluation, with baseline and follow-up after six months, of those who became first assistants in the period from November to December 2013.

This resulted in the following findings:

- › Significantly increased knowledge of mental illness among the elderly
- › Significantly improved readiness to help people in various emergency situations
- › Significantly increased helpful behavior when dealing with people with mental illness
- › Significantly more positive attitudes toward people affected by mental illness.

Quality-assured welfare

Through Quality-Assured Welfare, municipalities have been offered support in ensuring the quality of welfare services in eldercare, regardless of supplier. The municipalities have been offered the opportunity to participate in networks and to receive personalized support with the aim of improving follow-up. The objective has been to develop systems, procedures and approaches.

Toolboxes, checklists and templates have been produced and can be downloaded from <http://uppfoljningsguiden.se/>

Medication training

Working safely with drugs is a web-based training course aimed at employees in home care and eldercare before delegation. The course will be completed in March 2015 and is offered free of charge. It will be available via the “Knowledge Guide” (Kunskapsguiden) and the Swedish Dementia Center.

Mission Knowledge

In cooperation with the Swedish Institute for Health Sciences and Bodil Jönsson, Professor Emerita, 20 seniors with professional backgrounds in health-care have been given the opportunity to structure and deepen their knowledge under academic leadership. The aim was to utilize the seniors’ knowledge and extensive experience for the benefit of better health and social care for the most severely ill elderly. Course literature included *The mature mind* by Gene D. Cohen. A Swedish translation was made available through the Better Life initiative. *Den mogna människan* is the book’s title in Swedish.

Passion for Life

Passion for Life gives seniors the knowledge and tools to independently lead healthy lives. The idea is to engage seniors in taking active responsibility for a preventative approach to their own lives.



The Passion for Life approach involves a group of seniors meeting six to ten times at so-called Life Cafés to discuss and reflect on different parts of their lives under the guidance of a trained supervisor. The Better Life initiative has contributed funds to increase dissemination of the approach. The program won First Place in the 2014 European Award for Social Innovation in Ageing.

Program for specialist physicians

As part of their training, specialist physicians have an objective (Objective 20), which deals with leading and implementing an improvement initiative that will benefit their organization and patients. The aim was to build on the existing experience of improvement projects and the space available for each specialist physician, and develop a new way to support improvement initiatives. The program was linked to Ledningskraft and 42 physicians participated in it.

Research activities

For three years, 19 research projects on coordinated health and social care for the most severely ill elderly were granted funds for testing and development. A summary of this work has been published, “19 Ways to Cooperate Better”.



CHAPTER 8

On the right path, but a long road ahead

In the Better Life for Elderly Sick People initiative, several general areas for change in health and social care have been dealt with and concretized. These are listed below:

- › From illness to health
- › From reactive to proactive and preventative
- › From organizational focus to individual focus
- › From traditional treatment to users and patients as active co-creators
- › From individual healthcare contacts to inter-professional teams



1. identify. 2. assess. 3. follow up. 4. act. 5. plan.



What is important to you?

Proceeding based on the sick elderly person and his or her needs is essential to achieving good results for sick elders and for using the shared financial resources and appraisal tools effectively.

Today's healthcare system is designed to fit situations in which one illness is treated at a time, but is less conducive to treating people with diffuse symptoms and many illnesses concurrently. Women and men with extensive needs for input from multiple care providers need to be treated with a holistic perspective.

The approach that we are all different as individuals means that care plans must be individual and developed in collaboration with the elders and their relatives. Involving those we are here for in the process increases the possibility of taking advantage of the inherent healing power that exists in every human being.

Doing everything possible does not always create added value. Or, to put it in another way: most possible care, or best possible care?

It is possible to work in another way and still achieve better quality at a lower cost. A large number of promising initiatives based on inter-professional teams are currently underway. The prospects for disseminating and further developing these approaches need to be improved.

Health and social care in the home

The opportunities for elders to keep living at home are increasing and will continue to increase as medical and technical solutions continue to evolve. People with chronic illnesses must be well informed of their treatment and the signals they need to watch for. They also need simple ways to communicate with care providers. A direct telephone number to a nurse brings great peace of mind. Heart failure and COPD are two common illnesses that currently lead to many avoidable hospitalizations and re-hospitalizations within 30 days.

Hospitals are a risk environment for frail elders. Fall injuries, pressure sores, care-related infections, and confusion are some of the care injuries that often affect elderly people at the hospital, often with dire consequences. Preventative work and opportunities for emergency care in the home are important areas for development that must be prioritized. There are good examples of this.

The municipalities have taken over responsibility for home care throughout the country except for in Stockholm County. Physician treatment is still provided by the county council. This places great demands on effective interaction and effective routines. Assistant nurses working closest to the elderly patients have knowledge that needs to be better utilized. At the same time, staff in municipal health and social care institutions must always have quick access to physicians who can make assessments and even home visits as needed. Cooperation with relatives is also important.

In 2014, the county councils began measuring and compiling monthly reports on the number of hospital patients who are ready for discharge. There have been large variations in this. It does not stand to reason that elderly sick people should have to stand in line to get home. New approaches in municipal and primary care show that it is possible to work in a different way.

Rehabilitation

Rehabilitation after illness and injury is important in order to return to an autonomous life. Hip fracture and stroke are common reasons that older people today become dependent on others. Methods for rehabilitation are available, and need to be better utilized. No one should have to be helpless unnecessarily.

Technology at the service of the elders

New technology is often identified as an important opportunity to improve and streamline health and social care. Increased integrity, autonomy and security for the older person are achievable even now. When staff receive the

technical support to do things right from the beginning, quality and security in health and social care are enhanced. The time is ripe to raise the tempo in these efforts.

Standardized, structured and preventative approaches

To stay one step ahead and work in a structured and evidence-based manner, care processes must follow the same steps every time. This is standard in every maternity and child health clinic in the country. Sweden also has among the world's best results when it comes to survival rate and health for both mother and child.

The Senior alert quality registry supports a standardized approach in which preventative measures are implemented each time a risk is detected. The dissemination of this approach has been rapid with the help of performance bonuses. It is now important to keep at work, improve causal analyses and increase the quality of instituted measures.

With structure and systematics, eldercare can be improved. The variation in results will decrease and the floor of the lowest level can gradually be raised.

Joint management and administration must continue

Municipalities and county councils in all counties have now found their own ways to organize joint management and administration in the area of eldercare. Forums are in place at the political level and at the level of officials. An action plan for the joint improvement initiatives is produced annually. The key is loose collaboration with structured dialogue. Necessary decisions are made by each principal in the regular line organization or in joint quorums. Effective resource management requires a big-picture perspective. Collaboration among the principals is a key issue.

Management and administration based on results

It is always possible to find measurable goals that can describe at least part of an organization. Measuring and following up brings knowledge on what the system actually delivers as opposed to what it was thought to deliver. This knowledge can be used not only to set goals and work with improvements, but also for prioritization and comparison. Metrics and indicators must be continuously developed and refined to be as relevant as possible, but can never say everything about an organization or operation. These must be supplemented with qualitative follow-up methods and with patient-reported results.

Infrastructure for knowledge management and improvement initiatives

Concurrently with the Better Life initiative, work has been carried out within the framework for the agreement on evidence-based practice. The purpose was to build an infrastructure for knowledge management at a regional level. Government aid has been granted to regional platform leaders and to development leaders in different social areas. In the action plan for 2014, the counties have described how continued support for improvement initiatives and development leaders may be provided.

Moving from some to all

The goal of reaching all employees working in health and social care for sick elderly people is ambitious and there is still much left to do before the new approaches are commonplace in all organizations. The work that has been started must continue to receive support and encouragement.

Continuous improvements in everyday life

Continuous improvements as a natural part of day-to-day operations is a given in most sectors today. Expert knowledge must be supplemented with knowledge and methods for dissemination and improvement initiatives. We all have two jobs. Our job itself and the job of developing the system we work in.

IT support

Improvements that must be made in order to make health and social care for elderly sick people more effective include developing IT support for sharing information between care providers.

Health and social care employees also need to have access to a current list of medications that is easy to access. Opportunities for simple documentation in medical records and registries need to be further developed.

The work with the “A Better Life for Elderly Sick People” initiative has meant changes in many areas, but there is still much left to do.

“We’ll never be finished and we’ll always be on the way.”

Thank you

A political initiative and agreement has made the “A Better Life for Elderly Sick People” initiative possible. We would like to thank former Ministers Maria Larsson and Göran Hägglund for their dedication, cooperation and participation. Likewise, Staffan Werme, chairman SKL’s Primary care and Elder-care Committee.

We would also like to thank the Ministry of Health and Social Affairs through Eva Nilsson Bågenholm, National Coordinator for Elderly Care, and officials Gert Knutsson, Maria Nilsson and Monika Malmqvist.

Realizing the initiative required the assistance of 75 driven, positive, resilient and skilled people to be development leaders. Without you, this would have never been possible!

Nor would it have been possible without the quality registries. Thank you, Joakim Edvinsson, Anna Trinks, Susanne Lundblad, Kicki Malmström and Jesper Ekberg from *Senior alert*; Greger Fransson, Monika Eriksson, Marita Trulsson from *Swedish Register of Palliative Care (SRPC)*; Maria Eriksson, Ann-Katrin Edlund, Susanne Sjöberg from *SveDem*; Lennart Minthorn and Eva Granvik from *the BPSD registry*; and Ruth Öien from *RiksSår*.

Coach

Absolutely invaluable support for our work was provided by Dr. Sarah Fraser, British expert on large-scale change. Dr. Fraser has, with perseverance, enormous drive, constructive criticism, and her heart in the right place, coached our entire team from start to finish.

Cooperation

We have also surrounded ourselves with “critical friends.” These have always been there, listened to our thoughts, cheered us on at times, and made us rethink things at others.

We would especially like to thank the following people for support, good advice and encouragement: Bodil Jönsson, *Professor Emerita*. Michael Bergström and Kristina Jennbert, *experts from SKL*. Hans Gennerud, *communication advisor with Gullers Grupp*.

Sten Boström, *PRO*. Lars Nilsson and Gösta Bucht, *SPF*. Elsa Ingesson, *Passion for Life*. Ann-Christine Baar, *senior*. Robert Lloyd, Carol Haradan, Path Rutherford, Marjorie Godfrey, Maureen Bisognano, Douglas Eby and Paul Batalden from the *Institute for Healthcare Improvement, IHI* and Sir John Oldham, *NHS, England*.

Consulting firms *Health Navigator* and *Health Care Management* contributed with data for reports.

Steering Committee

Agneta Jansmyr, *Director of County Council of Jönköping*. Staffan Isling, *Chief Executive Officer, Örebro*. Göran Stiernstedt, Roger Molin, Hans Karlsson, Sabina Wikgren Orstam, Åsa Himmelsköld, Åsa Furén-Thulin and Annika Walenskog *all from SKL*.

The Webbkollen gang

Lasse Bourelius, *Blekinge Institute of Technology*. Magnus Olander, *Quicksearch*. Anette Lindberg, *Jämtland*. Annika Davidsson, *Blekinge*. Anita Gustavsson, *Norrbottnen*. Sarah Lundberg, *Västerbotten*. Tina Källberg, *Sörmland*.

Other contributors to the initiative

PhD student Helena Strehlenert and university lecturer Monica Nyström, *Medical Management Center, Karolinska Institutet*, have followed the initiative from the start. Two of three planned scientific articles have been published thus far.

The initiative has also been followed by *the Swedish Agency for Public Management*, with Jan Boström and Hanna Andréa as principals. A final report will be published in autumn 2015.

The SKL team

Over the years from 2010 to 2014, the team has consisted of Maj Rom, *Project Manager*; Ejja Häman Aktell, *Project Manager, Development Leaders and Quality Registries*; Anette Nilsson, *Project Manager, Ledningskraft*; Sofia Ek and Sara Rydell, *administrators*; Agneta Brinne, *Project Manager, Webbkollen*; Pernilla Askenbom, *Senior Advisor Communications*; AnneMarie Awes, *Communications Officer*; Cecilia Littke, *Web Editor*; Jan-Olov Strandell, *data compilation and analysis*; Nina Viberg, *pharmaceutical expert*. Ulla Gurner, *investigator*, conducted a base situation analysis and compiled a qualitative follow-up on the elders' health and social care contacts. Sofia Jonsson, *pharmacist*, developed an online course for safe medication management – Working safely with drugs.

Publications and films

The following materials have been produced by SKL

Publications

A Better Life for Elderly Sick People – a qualitative follow-up

Fyra områden för att undvika onödiga sjukhusvistelser (“Four Areas to Avoid Unnecessary Hospital Visits”)

19 sätt att samverka bättre (“19 Ways to Cooperate Better”)

Ledningskraft (Empowering change) – Designing managerial support in large-scale change management.

Performance Report 2012, 2013

Analysis Report 2012, 2013, 2014

Publications are available on skl.se

Videos

Improvements that make a difference – How systematic work with quality registries produces better results for the elderly, Swedish and English versions.

Important When I Get Older – about Ingeborg, age 93. Swedish and English versions.

Margareta’s Way – Margareta, age 77, talks about her situation. Swedish and English versions.

Working Safely with Drugs – discussion with Rut, age 91. Swedish and English versions.

SIP in 3 minutes – Coordinated Individual Plan

All videos can be viewed on www.youtube.com/user/SKLkommunikation.

Online resources

Data online – kvalitetsportal.se

Interview tool – webbkollen.com

Working safely with drugs – demenscentrum.se/webbutbildningar

Notes



A Better Life for Elderly Sick People

Major improvements over a short time

A Better Life for Elderly Sick has been made possible through a framework agreement between SKL and the Swedish government on *Coordinated health and social care for the most severely ill elderly people*, in which annual agreements were made from 2010 to 2014.

At the start of the initiative in 2010, interviews were conducted with nearly 300 sick elderly people who had a large consumption of health and social care. They spoke about a system in which it was easier to call for an ambulance and go to the hospital than get an appointment at the medical center. Every fifth sick elderly person admitted to the hospital was re-admitted within 30 days. The use of inappropriate medication was high, as was the number of drugs that were prescribed simultaneously.

Today, five years later, health and social care staff are working with new standardized, common and evidence-based approaches. Systematic appraisals and risk assessments have led to the implementation of preventative measures and it is now possible to follow key results in real time. Improvement initiatives implemented in regular operations lead to results. The desire to learn and improve emerges when the team together reflects on their results.

It is possible to implement major improvements in a short period of time!

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