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INNOVATIONS FOR SUSTAINABLE HEALTH AND SOCIAL CARE

VALUE-CREATING HEALTH AND SOCIAL CARE PROCESSES BASED ON PATIENT NEED

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About VINNOVA

VINNOVA, Swedish Governmental Agency for Innovation Systems.

VINNOVA´s mission is to *promote sustainable growth*
by funding *needs-driven research*
and developing *effective innovation systems*.

Through its activities in this field, VINNOVA aims to make a significant contribution to Sweden´s development into a leading centre of economic growth.

VINNOVA's objective for its activities in the field of Services and IT Implementation during the period is to conduct proactive programme work in order to generate broad-based R&D projects in which researchers and clients, in the form of both private and public players and users, are involved already at the ideas stage. The aim is to set up interdisciplinary projects in new areas and to revitalise thinking about, for example, the use of IT in the service sector. VINNOVA should act as a catalyst and gather researchers and users together to address various themes. VINNOVA should also play an active role in the development and follow-up of R&D projects so that they achieve the radical renewal desired.

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Research and Innovation for Sustainable Growth.

Innovations
for sustainable
health and social care

Value-creating health and social care processes based on patient need

Sune Andreasson
&
Monica Winge

Foreword

Through this publication, VINNOVA wants to publicise a project that was funded under the “catalyst programme” from 2005-2008. This project area is considered politically important and receives special emphasis in the Swedish “IT Strategy for Health and Social Care”. The project described the prospects of a “value-creating health and social care process” and since its conclusion has resulted in good, interesting ideas and solutions. It also highlighted pressing areas for ongoing research.

Sweden is still at the stage of not having successfully developed sustainable IT systems and e-services which can support changes in the patient’s role and good, interconnected health and social care for the patient.

VINNOVA’s therefore poses the question: What are the causes?

- Is there a lack of customer competence relating to the sector and patient needs?
- Is there a lack of knowledge as to how IT support should be developed?
- Has the development of IT been too focused on technology?
- Is there a lack of knowledge about IT and its opportunities?
- Is there a lack of capacity and incentive to renew healthcare and develop collaboration?

The project has attempted to elucidate these questions, seeking relevant answers from “Health and Social Care in Sweden”. This paper is based on the final report of the Value-Creating Healthcare Process (or VVP) project.

It is VINNOVA’s hope that this publication may be read by and provide inspiration for politicians, researchers, entrepreneurs and care providers in various positions within health and social care. Last but not least, it is intended to arouse interest and provide food for thought among public decision-makers in the health and social care sector.

The project was instigated by Monica Winge of Karolinska Institutet (KI) and Ulf Essler of Stockholm School of Economics (SSE). It has been variously led by Ulf Essler of SSE, Monica Winge of KI and Uno Fors also of KI. Other participants included Sune Andreasson of Intercare Connexion AB, Lars-Åke Johansson of Alkit Communications AB, Linda Soneson of KI, Margaretha Strindhall of Jönköping LL and Per Andersson of SSE. Major thanks are due to everyone from various operations in Jönköping, Gothenburg and Stockholm who contributed their knowledge and experience to the project. Particular mention should be made of the contribution by the staff of Qulturum.

VINNOVA, January 2010

Ulf Blomqvist
Head of Department
Services & IT Implementation

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1 Introduction

It is highly likely that the need for health and social care will increase in Sweden over the next 10 years and particularly from 2020, when the baby-boomers of the 1940s will be over 80. Studies indicate that Swedes have the best health in Europe and that the differences are great [1]. This does not mean that health and social care is functioning satisfactorily and especially not for those with comprehensive care needs – often elderly people and those with multiple illnesses. This has been observed and documented over many years. It is highly likely that coordination problems are greater in metropolitan areas with a greater offering of health and social care services. With freedom-of-choice reforms making it easier to set up new ventures, this problem will increase. The role of relatives in nursing has become increasingly important [1]. At the same time, it appears that society's health and social care resources are unable to expand to the true extent required by increased care needs.

Thus, health and social care resources need to be used more effectively and various efforts should be better coordinated so as to achieve better collaboration between health and social care personnel and not least of all with patients and relatives.

A number of reports and past projects have criticised the existence in modern healthcare of major coordination deficiencies between the various actors. Accordingly, projects such as SAMS, which ran from 2002-2005 [2] have concluded that:

> *"Today, there are many people involved in healthcare around the patient and each actor has their own access to information. It is difficult for everyone involved to know what is happening around the patient. Tackling the job of home care for patients requires forms of health and social care to be developed and IT support improved towards better coordination. Thus, actions carried out by different actors around the patient can be harmonised, providing good quality to the patient"*.

Even though SAMS developed models and system components for improved collaboration in health and social care, it has not been possible to turn these results into products and e-services which could be distributed and contribute to improvements.

The MobiSams project (2004-2006), which attempted to progress the results of the SAMS project and link the integrated ICT components proposed by SAMS further into a mobile environment, confirmed that in current healthcare, coordination is anything but optimum. Amongst other things, it was noted that:

> *"For a number of patient groups, caring for patients based at home can provide better quality and lower costs than institutional care. It would*

> *also be possible to care for more patients and entirely new patient groups at home than is currently the case. However, achieving qualitative health and social care in the home requires good coordination between the actors participating in health and social care of the patient, including the patient themselves and their relatives. This coordination has not been sufficiently implemented today"* [3].

Other projects which have arrived at more or less similar results are TILLIT, old@home and VITA-Nova; projects which ran during roughly the same time period and were funded by VINNOVA and others.

Reports from the Knowledge Foundation and in the National IT Strategy [4] indicate that it is essential for the coordination between different health and social care providers to be improved and that there is a growing focus on individual needs and safety. Above all, information systems must be changed so as to actively support such a development. In conjunction with the National IT Strategy, a number of national initiatives and projects have been started in order to influence developments in the direction indicated. Legislation and rules are also undergoing change.

Thus, it has been demonstrated that there are major deficiencies in coordination between healthcare actors and that these are leading to poor quality care up to and including direct risk to the patient. SAMS, MobiSams and other projects such as the EU's Intercare project [5] have concluded that it should be possible to initiate good models of coordination and that these may be even more effective with IT support targeted for such coordination.

Future health and social care will be run under entirely different conditions than currently. Above all, the roles between health and social care personnel and patient will be changed. Patients and relatives will be more active and gain greater influence over the health and social care that is provided. Therefore, it becomes much more important to understand what creates value for the patient. The Swedish Board of Health and Welfare has brought out this dimension in its publication, "Good Healthcare" [20] and it has been an essential basis of the VVP project.

There is great confidence that the Internet and new e-services will be able to contribute to improvements in healthcare and enable the formation of innovative new care concepts. This is despite the fact that IT companies have so far not succeeded in delivering the effective, flexible ICT services currently required by healthcare. Future needs and requirements will only be greater.

Swedish healthcare has an internationally high profile and this also applies to our capacity to apply ICT in developing operations and making them more efficient. A combination of healthcare and ICT has long been considered an opportunity for Swedish companies and organisations to progress on the international market.

VINNOVA will work for sustainable growth and sees an opportunity to promote this through this type of project.

This was therefore the background to the commencement of the *Value-Creating Healthcare Process* (VVP).

2 Summary and conclusions

This report has been compiled in an attempt to describe how the results of the VVP project might be used to develop health and social care for elderly patients with complex needs. For more comprehensive documentation, reference should be made to the final VVP report with appendices.

The target group of this report is operational managers and developers working to improve health and social care for elderly people and those with multiple illnesses. We are addressing system arrangers such as politicians and those at management level in municipalities and county councils, since it is they who must create the conditions for the necessary improvements. Elderly people themselves and their relatives (those who must bear the consequences of current health and social care deficiencies) may be interested in our proposals and use them in a constructive dialogue aimed at change and improvement.

We commence by describing the current state of health and social care. This case is authentic and startling, but not unique. This is supplemented by some observations of ongoing development work, chiefly process development. The subsequent section offers a brief account of our external analysis during the project. There is an awareness of the challenges associated with the increasingly ageing population. Many people consider the current healthcare system unable to meet these needs and that radical change is required. The emerging picture is one of healthcare with greater diversity, significantly more public and private care providers and a more involved patient whose relatives also have a much more important role in their care. There will be an increasing element of preventative measures in health and social care and improved opportunities for elderly people to have advanced health and social care at home. Hopes are running high that information technology (ICT) and e-health will open up new opportunities and lead to innovative solutions.

The VVP project has been working towards the objective of trying to create a new patient-centred and pro-coordination healthcare model which, aided by tailored support from appropriate e-services would be able to create increased value for patients and relatives as well as care actors themselves. It has thus become a central theme of the project to seek increased understanding of value and value creation as such. One hardly surprising but important conclusion is that the perception of what is value and, above all, what creates the most value is highly individual. In safeguarding value creation, one of the fundamentals of the healthcare model must be to ensure continuity and participation.

We have also found it vital to gain a deeper understanding of what the collaboration means between different authorities focusing on the individual’s situation. This provides major opportunities for generalisation and opportunities to impact many different patient groups. In the project, we have also worked on such issues as patients/users with neuropsychiatric disorders.

One important conclusion from the project is that an increased focus on process orientation and what builds value for the individual is placing new demands on how health and social care is organised and controlled. It is the patient’s process which is central, not the various health and social care processes which involve or concern that patient. Naturally, this in turn leads to entirely new demands on how the e-services should be designed in order to achieve the desired effects for the individual.

The most significant result of VVP is the proposal for a new healthcare concept. This concept is based on a three-level structure:

- Patient level
- Intermediate level – the care team
- Outward level – the network of external consultants/experts.

The VVP project proposes that a collaborating/coordinating “conductor” be introduced into healthcare. We use the term *care coordinator.* The care coordinator has an express mandate to lead the work of the team surrounding the patient and order other services as required.

Another special aspect is the “Project idea”, i.e. the team surrounding the individual/patient is needs-adapted and set up according to current need and the fact that the actual process is based on the individual as a whole and not the illness/health and social care process concerned. In other words, the individual is to be viewed as a whole with all his or her medical, mental, personal problems and circumstances. The patient is not “the hip joint”, “the eye” or “the stroke”, but an individual who may in turn have a number of different medical problems related to various conditions.

The idea of the VVP concept is also that there should be a constant flow of information between the three different levels and to all involved actors, including patients, relatives, municipal actors, county council actors and private actors. What information is disseminated to what type of actor depends on the situation and type of actor concerned.

Working with VVP has taught us that information flows and e-services are highly essential and that none of the current IT systems can support this new healthcare concept. The patient level needs different e-services to the team level, which in turn needs different services to the external/specialist level.

This very likely opens up a new market for new types of e-services which can integrate, communicate and visualise information in a new way. To become attractive on the market, these new e-services probably need to be grouped into larger or smaller “clusters” of logically and technically linked e-services.

The new care concept must have a chance to be further developed and clarified and do this in conjunction with health and social care. VVP has also specifically studied this and concluded that a well-functioning incentive structure is currently lacking which could obtain broad implementation of the results of VVP and other innovative projects. There are many institutional obstacles which must be moved aside and some of these measures must be initiated on the political level.

3 A patient’s account and other observations from health and social care

Healthcare in Sweden is characterised by high quality and good access for everyone on equal terms. This is the way things have been for over 50 years and we expect everything to function as normal the day we get sick. However, something has happened in the last 10 years and more and more people are starting to notice a deterioration in the quality of healthcare and its availability.

To illustrate the situation of today’s healthcare, there now follow a couple of concrete examples relating to a patient and drawn directly from actual everyday experience.

An elderly woman (86) with multiple illnesses and double hip and shoulder replacements was recently readmitted for a knee replacement. The patient is also depressed, has a weak heart and has had a couple of strokes in the past year involving medication with blood-thinning agents. This medication has led to complications such as bleeding and has resulted in emergency hospital admission a couple of times. The patient also attended A&E a couple of months previously because an 18 year-old hip replacement had started to cause complications in the form of pain. Her list of medications includes some 12 different drugs to be taken at specific times during the day. The patient lives at home with a certain amount of support from the home-help service. Despite her age and her illnesses, she is mentally lucid and alert.

Example 1

The patient gets in touch with her son and says she has been asked to attend an orthopaedic clinic at the hospital. She doesn’t know whether it is for the new knee operation, the hip replacement, or a normal check-up on one of her shoulder replacements. The appointment letter does not state its purpose and she does not know whether or not she will be admitted.

Her son accompanies her to the clinic and calls the doctor’s attention to the fact that the patient does not know the purpose of this visit. It is then pointed out that there are three different referrals going to three different orthopaedic specialists at the same clinic, but that none of them are aware of each other’s referrals. The son requests that this be looked into. It turns out that one referral is for a check-up, another is for an examination prior to possible repeat surgery on the old hip replacement and the current referral relates to his mother’s admission that day for surgery on her right knee. Interestingly, his mother is admitted for her knee surgery despite the fact that postoperative rehabilitation will require her to be ambulant. This is difficult, because her hip replacement has come loose.

Example 2
The same patient as above, but two years on. The patient has now had further strokes and is so exhausted she has had to move into an old people's home. One night, she has a suspected stroke. The doctor for the home is called out as an emergency and refers the patient to hospital for tests and treatment for her suspected stroke. No staff accompany the patient to hospital; carrying only the referral from the care home, she is given a lift there in an ambulance car. The patient feels unwell and anxious. After a wait of several hours, she rings her son and he comes in. He speaks to the A&E nurses who say his mother will be seeing a doctor soon. This is three hours after her arrival with a suspected stroke.

The son goes home with a promise that he will be called as soon as his mother has been examined. As he hears nothing more from the hospital that evening, he rings again in the morning to enquire how his mother is. The answer is that they didn't have time to examine her, so she was sent back to the old people's home some nine (!) hours after her emergency admission with a suspected stroke. Nobody fed her, nobody investigated the suspected stroke and she saw no doctor.

The next day, the son compels the old people's home to send his mother back to hospital. At this point, it is confirmed that she has probably had a further, minor stroke. The staff at the home were adamant his mother had already been seen and was sent home because there was no stroke. No report came back with the patient.

This might sum up modern health and social care. It is important to point out that regrettably, the above examples are not unique. Similar accounts can be heard from far too many quarters in Sweden today. This lack of coordination is causing increased patient suffering and of course, problems for relatives and for health and social care itself, which is becoming needlessly costly and inefficient.

3.1 Impressions from field work and fact-finding

In this project, we have attempted to depict the current situation in health and social care through interviews and discussions and by examining reports and studies of various kinds. Since the problem of coordination is greatest for patients with comprehensive care needs such as elderly people, those with multiple illnesses and people with neuropsychiatric disorders, we have focused on these groups in this report.

Our interviews convey an impression of how health and social care personnel are saying they must often work in an unstructured and muddled reality. Factors which make their work function are contacts, networks and relationships on the personal level. Many also regard these as solutions to the problem of coordination. The problem with these solutions is that people change jobs, new actors appear and organisational changes break up functioning teams and networks.

It is most common when discussing healthcare processes to proceed from an image of stable, predictable processes based on scientific foundations – evidence-based healthcare programmes. This applies to a number of activities and a number of diagnoses. A broken femur can certainly be treated in a standardised fashion, but elderly people with complex health and social care needs spend most of their time in a reality that looks completely different.

Other assumptions apply to the care of elderly people and those with multiple illnesses. This is not a case of curing the patient, but of helping them manage daily life and various problems which arise and events which occur. Naturally, it is also a matter of relieving problems caused by illness rather than by being healthy – preventing or combating impairment due to their illness. The planning must be very much more dynamic. Additionally, not all elderly people have a homogenous understanding of what is value-creating, i.e. what should or should not be done.

The confused structures live side-by-side with straightforward ones. A case description for an elderly person might show that over a period of time, the patient received help from various people in a fairly unstructured fashion. Then the patient meets with an event (injury from a fall), requiring efforts which are structured and plannable (surgery). The elderly patient is then pushed back into unpredictable rehabilitation and ongoing care, which they must navigate as best they can aided by relatives.

It is often claimed that the work functions despite a lack of structure, because those in health and social care want to do good, do a good job and take responsibility. This is of course partly true, but when the patient is dependent upon different health and social care providers and is referred across organisational boundaries, then the problems emerge. All too often, audits by the Swedish Board of Health and Welfare highlight deficiencies in routines and systems. Another observation is that staff cannot always cope with defective organisation and routines – in fact, it is increasingly rare that they can. One of many reasons is that a conflict arises between what the individual healthcare staff member regards as important and which provides good care and the mandate of the unit where they work. These duties are often linked to economic constraints or results. Since managers are assessed on results, and since finance and budgets are put ahead of most things, the need to keep costs down can easily become more important than care. It is easier to demand responsibility when there is structure, clear objectives and guidelines. When unstructured and untidy healthcare is set alongside a foursquare economic structure, it is often easier to emphasise achieving economic objectives rather than developing health and social care.

Of course this is unsustainable in the long term. Health and social care for elderly people (those with multiple illnesses) and groups with special needs (such as those with neuropsychiatric disorders) must be better organised and implemented. Even now, we would maintain that the difficulty does not lie in designing a vision or model for how a chair chain or process should look, or how healthcare ought to be organised. Rather, it is a question of setting up change management which leads to genuine and sustainable improvements. A good example is the work of developing interorganisational collaboration which commenced 10 about years ago in Eksjö with Esther (www.lj.se/esther). This has been a success and gained such accolades as the Götapriset award. Perhaps even more notable is its inspiration of others to start similar projects so that many other elderly ladies like the symbolic Esther can now hold regular family gatherings to learn and exchange information. Another example worthy of mention is an initiative taken in Västra Götaland where a number of hospitals have created teams to develop a better understanding of the overall picture and patient's situation upon discharge from hospital.

3.2 Working with care chains and health and social care processes to create structure. What is the current situation in healthcare?

Another phenomenon which we studied in the project is process development [6, 28] or the currently popular concept of "Lean". There is a more comprehensive account in the project report, so we will only summarise it briefly here.

The first projects aimed at flows and care chains commenced at the start of the 1990s. The Federation of Swedish County Councils then initiated a project called SamkraftVård which began amassing healthcare knowledge [7]. Many care chains have improved learning in recent years but only in recent years does the work seem to have picked up speed. International studies to date in this area indicate that using process innovation is a way to address internal problems such as flow and coordination within healthcare, rather than customer focus problems [8, 9]. But does this apply to Swedish medical care?

In summary, it can be said that interest in process development and Lean has evidently increased in the past year and a clearer customer focus has come about. So far, the initiative has most often been taken in specialised programmes related to the treatment of patients with a particular diagnosis. Hospital management has shown increased interest and aided the process in becoming increasingly interorganisational.

Interviews were conducted with a number of people who had a good overall take on things. One of them had a more intuitive appreciation of the fact that Swedish medical care was scoring two or three on a scale of 10, with 10 indicating that we had realised the full potential of the process-orientated development work.

Another aspect which interested us is whether the process development yielded any results in practice. Or was it a case of enthusiasts and dedicated teams describing and creating (or recreating rather than designing) processes, only for the reports to end up shelved whilst the operation went on in the same old rut? This may be the case in many instances but in his thesis [10], Johan Thor at Karolinska Institutet demonstrates that 58 percent of process development projects have led to tangible improvements.

Some were doubtful as to whether the major projects instituted by hospital management led to the anticipated results, with the possible exception of private hospitals where people “are more adept” at copying working solutions. The principle of self-organisation is strong in healthcare and has a long tradition, meaning that “top-down” approaches seldom lead to anticipated results. However, management initiatives such as those above mean that knowledge about the process development trickles down in the organisation and can thus support and encourage local initiatives. What then happens is that someone implements improvement measures in areas they control – the individual operation. As soon as the process becomes interorganisational, the problems grow.

Leadership at departmental level is important if process development is to function, but it is not always the main problem when it does not. More often than not, the deadlock is “one floor up” and associated with financial control. Financial control takes precedence, which is why development work often remains on the level of maximising benefit to individual departments. As someone rather drastically put it, politicians and top-level management have financial control as their only means of coercion and it is handy to maintain a tight grip on it. This makes it difficult to implement changes which from a holistic perspective are financially justified, but which may lead to poorer results for any of the parties concerned.

Another problem is the boundaries between professions. Even so, the work in interprofessional teams has been gradually developed and there is now a broad acceptance that interprofessional teams are a success factor in development work.

In many cases, with our clear focus in VVP on value creation and the customer/patient, we also noted deficiencies or limitations in ongoing process development. Healthcare programmes, clinical guidelines and evidence-based healthcare only come into play once the problem has arisen. The effort is seldom broadened to forestall or prevent the problem from arising and for the patient, forestalling or preventing illness from arising is intimately associated with their experience of value.

All too often, we see the patient treated as “a kidney”, “a heart” or “a stroke”. Of necessity, services are becoming generalised and in the best cases when subsequently carried out, they are tailored to the specific circumstances of the patient concerned. On the other hand, it is seldom considered that a patient may have several ongoing parallel processes. What does this mean for value creation? There are risks associated with too much process-orientation based on diagnoses; it can fragment and prevent system-mindedness and diminish opportunities to see the whole picture. A complementary approach is required at this point – the patient's process. In today's health and social care, there is seldom anybody taking responsibility for that perspective; it is the patient's problem to manage. This raft of problems has not been given adequate attention, but has been addressed in a report from the Development Department in Region Skåne [11].

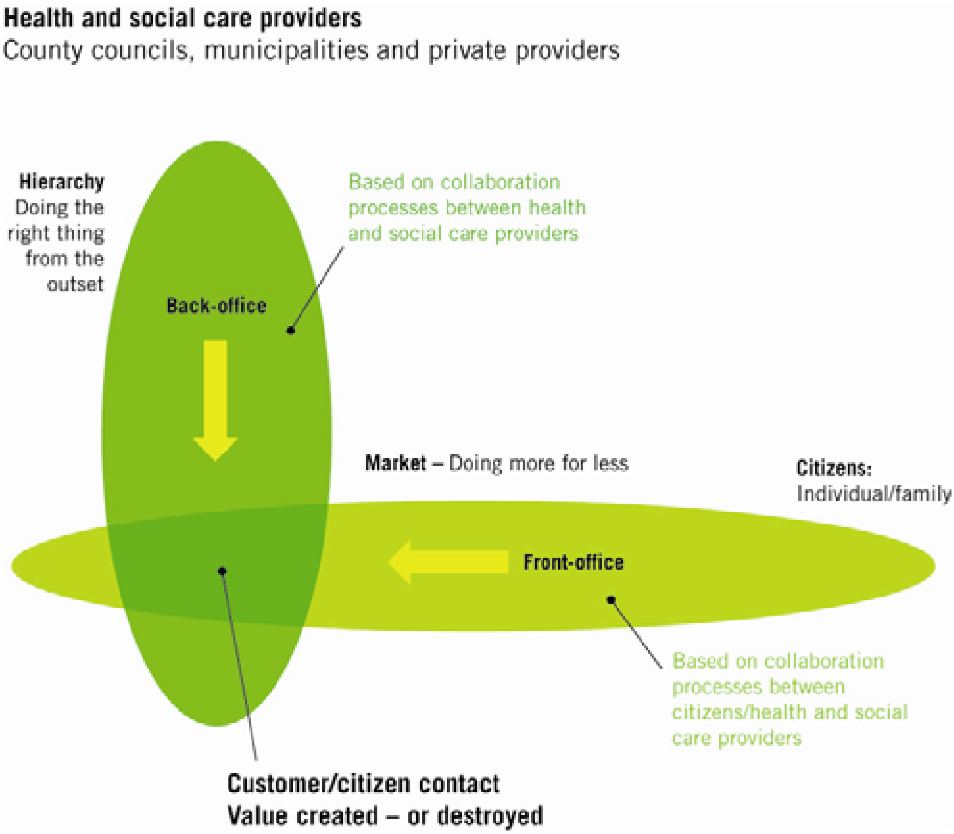
To aid increased understanding of the ongoing report, we would emphasise at this point the difference between a (patient-orientated) healthcare process and the patient process (the patient's own process):

- The healthcare process (even if patient-orientated) is created from a production perspective.
- The healthcare process can be made more efficient using the Lean method etc.
- Healthcare processes most often describe logistical flows.
- A patient may be involved in a number of parallel healthcare processes (often not coordinated).
- The patient process starts with the patient and has a recipient/holistic perspective.
- The patient process also includes activities which do not originate from healthcare processes.
- In the care process, the patient is the object.
- In the patient process, the patient is the subject.

4 Value for the patient

Ultimately, all the efforts made in health and social care are to create value for patients in various ways. One hypothesis in the VVP project has been that increased knowledge on how value is created can contribute to improved, more efficient healthcare. Having value creation as a starting point for process and organisational development can advance our efforts to improve health and social care.

This section starts with a somewhat theoretical attempt to describe and define value and value creation. There then follows a discussion of what creates value in healthcare with concrete examples in which we also indicate opportunities for supportive/enabling e-services (some of which already exist in some quarters).

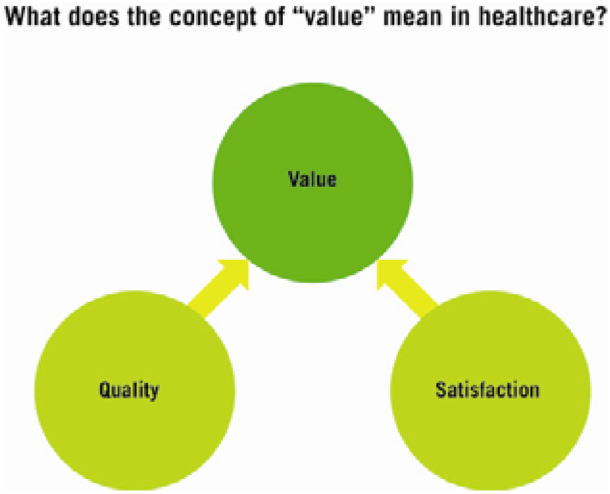


The diagram describes the encounter between the citizen and the health and social care system. “Front-office” relates to parts of the organisation which have customer contact. “Back-office” relates to parts of the organisation which do not.

The distinction is discernible at this point between a care process and the patient process. In the “back-office” segment, the operation is designed to be “right first time”. The various activities should fit together efficiently and there should be optimum logistical function. In the “front-office” segment, things should work well for the health and social care recipient at the interface between health and social care actors.

Accordingly, the definition of value is a clearly defined “co-creative” process in which the citizen is satisfied with a process which cures the symptom and a healthcare actor who is satisfied with a process that solves the problem. Symptom (satisfaction) and problem (quality) are two intertwined threads which jointly create value.

4.1 What does the concept of “value” mean in healthcare?



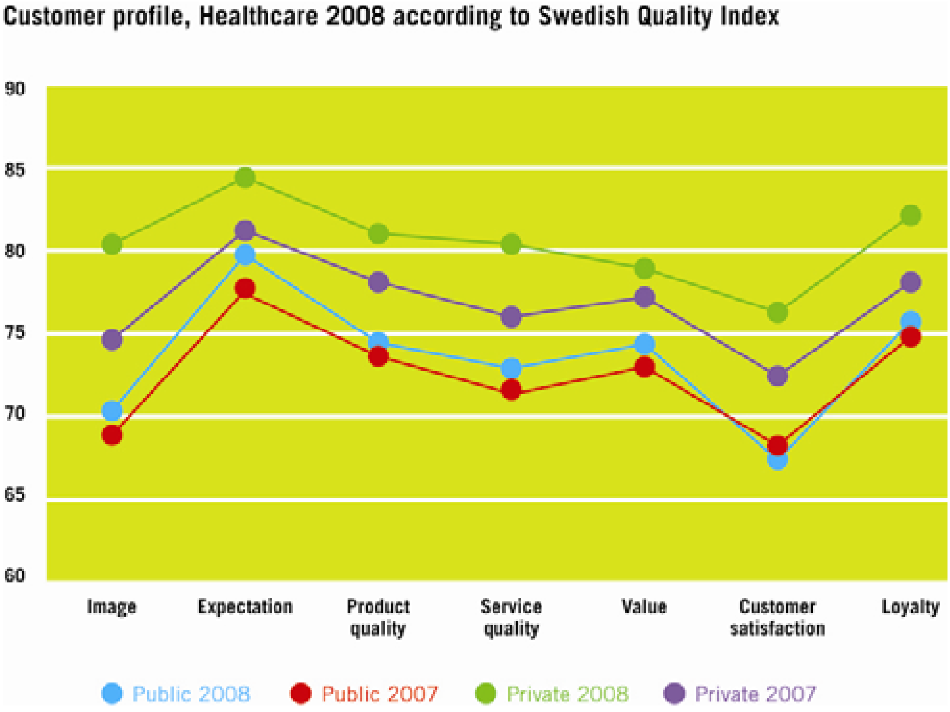
This simplified diagram illustrates the requirement for both good technical/medical quality and good service quality in order to create value for the patient. The concept of value can then also be extended with a resource dimension; this is particularly relevant when discussing value in a system perspective. Brent James defines value by the formula:

Value = (TQ + SQ) / Resources

SKI (Swedish Quality Index) conducts studies of how patients and citizens perceive medical care, measuring seven different parameters including Image, Expectations and Loyalty.

This shows that there is no unequivocal definition of value, but rather that the concept of value varies according to the context or frame of reference.

In VVP, we have assumed that value is created by something being carried out at a good level of quality in a fashion which satisfies the recipient. High quality often leads to customer satisfaction. Outcomes and results are often important in healthcare; in other words, achieving the objectives of the effort, the patient getting well or pain being kept at a desired level. Another parameter of major significance for patient satisfaction levels is the patient's expectations. This depends on previous experience, knowledge of their own condition, what may be demanded and occasionally on personality. However, it is apparent that approach as well as delivery and process parameters are highly significant to how satisfied patient is. This becomes all the more important when a patient has more opportunity to select a health and social care provider.



On the other hand, we must also discuss whether “customer satisfaction” (or in this case “patient satisfaction”) is the ultimate measure of well-functioning, high-value healthcare. Some effort must often be expended in trying to satisfy the patient’s wishes, but there are also cases when, due to ignorance about their condition, unwillingness or for other reasons, the patient “wants the wrong thing”. A patient who wants narcotic painkillers should not always get them. A mentally ill patient is not always in a position to determine what is best for him/her. In the huge majority of cases, it is probably true that a development towards increased patient focus and a value-creating patient process will mean the patient gets better quicker and can also remain in better health in future. However, we are aware of an inbuilt conflict which has to be managed by the doctor/healthcare personnel. The doctor cannot always initiate medically justified measures if the patient opposes them and the patient cannot always get the treatment he or she wants if the doctor does not consider it medically justified.

It is difficult to define the concept of “value” when different people perceive it in different ways. This is particularly so in contexts as complex as medicine and healthcare. It is also probable that the perception of value in care differs between different groups, such as patients, doctors, nurses and administrators. Since the VVP project is based on a radical citizen-perspective, our focus in this chapter is on the patient’s own understanding of value and not that of the caregivers.

A radical citizen-perspective means:

- Value is determined by individual understanding of what is value, not by the healthcare sector’s assumptions or intentions as to what it is.
- Value is determined by individual usage of healthcare service, not by the healthcare sector’s production of it.
- Value is determined by what the individual gets out of the service and not what it costs to produce.
- Understanding what is important to the individual and how the organisation can get better at describing and clarifying the individual’s choices so they can get where they want to go.

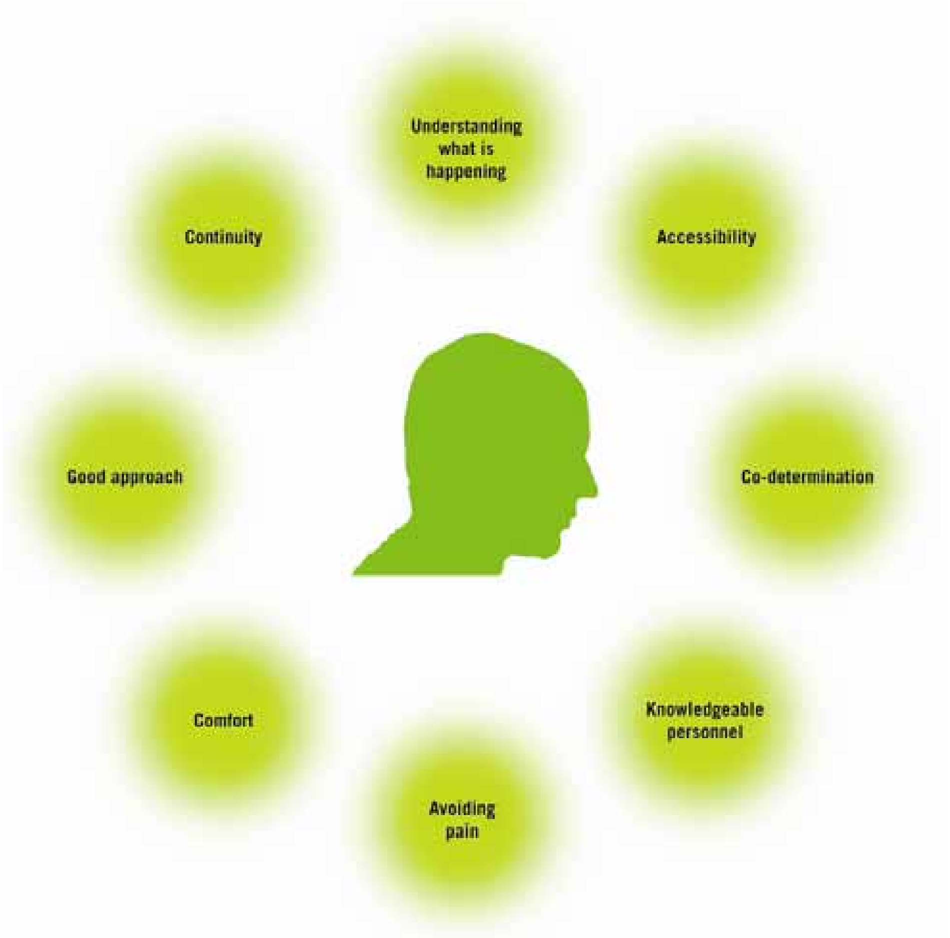
For someone who is on the point of purchasing something, the sum they are prepared to pay for a certain good or service normally reflects the value of that good or service. However, where it concerns health and social care which, at least in Sweden, are not associated with procurement or sales activities, the concept of value often means something entirely different. It may be the value of being healthy; the value of being able to be healthy; and/or the value of being able to remain healthy. In other words, the value of preventative healthcare. Also, for those who cannot achieve health, the value may perhaps lie more in freedom from pain; the value of managing their day-to-day activities; the opportunity to remain living at home towards the end and so on.

4.2 What creates increased value in healthcare?

If you ask different people what value is, there are often different answers: Value for money, valuable items, human dignity and valuable memories. The response may also involve values and norms.

Being healthy is probably the value which most people would rank among the highest. It often comes before good material standards and so on. From a VVP perspective, this strengthens the justification for extending the process to embrace preventative efforts and avoid illness.

Patients often maintained that they want “help to help themselves” and for healthcare to work more proactively to prevent them getting ill (again).



When someone is sick, they want to be well. If they can’t be well, they want any deterioration be pushed as far ahead in time as possible or have help managing their problems so that they can live the best life possible. The precise *workings of this process* are a vital measure of how patients value healthcare and the health and social care process of which they are a part. Many patients involved in the various VVP subsidiary studies can clearly describe when the health and social care process did not create good value. Things that diminished value in the health and social care process include long waiting times, unclear messages, poor coordination, a lack of respect or some other form of poor approach. It is probably the case that if the identified negatives were improved, it would lead to increased value in the patient’s eyes.

When patients and relatives are asked what could be improved within health and social care, access, approach and continuity stand out as the three most important phenomena of value creation. There may also be a large number of other contributing factors. In this project we have used interviews, questionnaires, literature surveys and discussions to pick up opinions on value in various ways. Below is a brief account of a selection of different phenomena which may appear in an individual’s “value map”.

Value of freedom from pain, staying at home, feeding oneself, functioning socially etc.

For many suffering with chronic illnesses or terminal conditions, a patient process that specifically supports them in their situation would be perceived as value-creating. Please note that once again, it is individually tailored solutions which are sought.

For example, a cancer patient will most often want to be pain-free; one with neuropsychiatric disorders may want support in managing day-to-day life and living on their own; a third person might value having advanced medical care at home in order to continue living with their partner/family despite a serious illness.

Some of this could probably be supported if not solved by new services and e-services.

Time perspective

The time prior to meeting a doctor, receiving treatment and/or getting well is one of the most common problems pointed out by the VVP patient groups. Frequently recurring wishes include everything from knowing the waiting time at A&E, to the waiting time before a specialist referral is processed and even being able to reduce actual treatment time. Cultural sociologist, Merete Mazzarella put it this way at this year’s primary care conference: “You never feel as powerless as when you’re waiting”. An important issue for many is insight and participation in the planning process.

Knowledge and information

In studies, both within VVP and in other investigations, a large number of people indicate their wish for improved information opportunities. As a patient, a person wants more knowledge about their illness or how to reduce the risk of getting ill, what has happened to their referral and so on.

There should also be a place here for new and improved services and e-services. Examples of services which already exist to some extent but which would provide greatly increased value if broadly implemented are:

- The ability able to use secure web services to consult your doctor, dentist or nurse regarding your own particular problems or issues.
- The ability to obtain personally tailored information via secure web services about treatment alternatives and their advantages and disadvantages.
- The ability to use secure web services to prepare for what to expect from the radiology department, radiotherapy, dialysis unit and so on.
- As above, but tailored to people with special requirements for receiving information such as children, elderly people, those who do not understand Swedish etc.

Relatively limited efforts can generate quite a lot of value for the individual. Simple e-services such as appointment booking via the Internet, opportunity to communicate with your own doctor or find out about your referral management process would provide a lot of value for a very large number of people.

Co-determination

Modern patients often want the ability to influence their own health and social care. Doing this requires access to information and knowledge. It may be a matter of choosing between two different treatment options, participating in care planning or something else. Co-determination is difficult in many complex conditions, but a web-based information service facilitating increased knowledge about your illness might serve as a support.

The free healthcare choice now being introduced in many quarters will mean an opportunity for increased patient power. However this does not solve all aspects of increased co-determination.

Approach

As stated above, more or less everybody appreciates a friendly approach and being treated with respect by healthcare personnel. Although VVP does not in itself focus on patient approach, it is probable that some new e-services and more coordinated healthcare would give health and social care personnel a little more time to deal with patients and thereby also time for a more open and valuable approach.

Our survey within VVP indicates that the majority of those interviewed consider approach to be directly linked to a sense of value (in-depth interviews with people living with ADHD and/or Asperger).

All of them had met with negativity from those around them and the educational system was singled out for particular criticism by both those living with ADHD and/or Asperger and their relatives.

Overview

Patients want an overview of what will happen next – waiting times, where the referral goes and what happens to it, what various types of healthcare personnel do (such as specialist clinic doctors, general practitioners, health visitors, home nurses and home-helps). It should also be possible to support this with new e-services such as:

- Booking and altering bookings for appointments at the health centre, dentist or hospital.
- Viewing the referral route – when it is sent, to whom, when it is dealt with and when the person is to meet those who will treat them etc.

Collaboration

Health and social care providers are seeking common guidelines for their field in terms of treatment, approach and care. Collaboration difficulties are most often due to a lack of communication between points of contact. More efficient health and social care processes create more value for the individual and their relatives.

Patients with complex conditions (e.g. those with multiple illnesses) expect that different healthcare information systems will be able to work together and exchange information with each other.

This means there are major opportunities to develop e-services which can keep the right information together and disseminate it to the right people including patients and their relatives. For example:

- Collaborating e-systems to link together different information systems in specialist healthcare, primary care, home nursing, home-help service and so on.
- A “patient component” for an overview of what information is flowing where; what treatment agencies will be involved and their results; who is responsible etc.

Continuity

We know that often, there are far too many healthcare actors surrounding elderly and chronically ill patients. In the home-help service, it is common for the patient to see a large number of different people in their home. A lack of continuity by responsible healthcare personnel leads to poor communication, making it difficult to gain a clearer picture of the patient’s overall health and social care situation.

Assurance

All patients (neuropsychiatric disorders) interviewed in the VVP Jönköping focus maintained that the network developed at the start of the survey and beginning of the health and social care process offered a basic assurance in the form of guidance and help in planning and establishing a functioning daily structure. This increases the chances of learning more about oneself and one's own situation.

Flexibility

In Jönköping, those with ADHD and Asperger and their relatives also wanted flexibility from the education and healthcare services regarding approach, teaching methods and care planning.

Correct competence

In order to meet the patient's needs, there is also reason to consider whether the operation has the right competence for its task. The current municipal operation may involve totally untrained personnel working as holiday cover in old people's homes and dementia care homes. On another level, there is also the problem that A&E units for example often lack competence in geriatric care even though elderly patients form a very large proportion of those attending A&E.

Access

The access problem, with long waiting times in several areas of the health service and difficulty getting in touch by telephone is of course unacceptable. In striving for a balance between need and capacity/resources, there should be a major ambition, based on realistic assignments, to plan operations that ensure patient-focused rather than organisation-focused access.

Participation/opportunity to influence

Relatives in Jönköping emphasised the importance of being offered the opportunity to participate in their children's contact with various units of society, since they have thorough knowledge of their children and can assist in remembering and recounting different meetings with, say, doctors.

Improvements in almost everything described above would increase the patient's experience of value in healthcare. Probably the most important thing is to begin seeing the patient as a vital healthcare resource and not as a disease or phenomenon. This assumes changed roles where healthcare personnel and patient jointly plan different healthcare measures and the patient's perception of what creates value has major impact.

Following overall information on the external situation in section 5, we will outline a model in section 6 of how patient and relatives can gain major influence in the ongoing care planning and in where various efforts are directly linked to problems, objectives and value creation.

5 Towards healthcare that brings about increased value for the patient

5.1 External situation

A review of articles on strategy documents from a large number of countries consistently shows that the healthcare system in its present form can manage neither the current challenges nor any that may be predicted [12, 13, 14, 15, 16 and 17]. Chief among these challenges are health and social care requirements. More and more people are getting older, more are being affected by one or more chronic illnesses and the growth of medical knowledge is making it possible to successfully treat an increasing number of conditions. Demographic estimates indicate that by 2020, 25% of Europe's population will be over 65. Some 60% of the world's resources are used on elderly care. Add to this patients with chronic illnesses and complex care needs and they account for a very large proportion of healthcare consumption – we estimate it to be over 70%.

Since there are major improvement needs – and opportunities – for these patients/users, we have angled the project towards these groups.

It has become obvious that the current system is based on outdated principles. It is consistently the case that radical changes are needed in the health and social care system. Some reports are drastic enough to state that 21st Century care cannot be provided through a healthcare apparatus designed on 18th Century organisational and management principles.

The visions and strategic directions which we have studied are, if not identical then variations on a theme. There is also a conviction that ICT has a key role and is a strategic prerequisite for realising visions of the new healthcare system.

In 2008, an EU programme commenced which will run until 2013 – the Ambient Assisted Living (AAL) Joint Programme [15]. The European Commission is contributing an annual budget of EUR 25 million whilst participating countries jointly contribute roughly the same amount. Combined with project co-financing by industry, the programme is expected to end up at around EUR 600 million over six years.

The background information highlighted the challenge faced by Europe in meeting the demand for care from an ageing population with an increasing incidence of chronic illnesses and often multiple chronic conditions. A "paradigm shift" in health and social care is required, characterised by:

- More individualised care
- More care in the home
- More preventative measures including risk assessments
- More self-care
- More and better information management.

In a report compiled on the instructions of the European Commission, the situation was described as follows:

> *"Furthermore, chronic diseases are on the increase, as are their management costs. All these factors are starting to place additional strain on European healthcare systems. The emerging situation will not be sustainable unless action is taken at all levels to change the way healthcare is delivered."*

The report "Health Informatics Review" from the Department of Health [14] establishes that the need for high quality information within the NHS and social care in England has never been greater. Conclusions and recommendations are based on a comprehensive dialogue in which 1,400 partners took an active role – NHS employees, patients, the public, voluntary organisations and professional organisations. The report brings out a vision characterised by fair, needs-adapted, safe and efficient healthcare of high quality.

The huge majority who took part in the dialogue considered access to information was crucial in achieving the high level of patient safety, quality, patient experience and efficiency which may reasonably be expected.

There is also a clear realisation that ICT cannot "exist in isolation". The necessary changes in the medical care system govern which services need developing. The patient wants to know what alternatives are on offer so as to make their choices. Healthcare personnel need reliable and relevant clinical information to give the right treatment to patients. The public expect that those leading health and social care will guarantee quality in healthcare by basing decisions on science and trusted experience.

In Canada, the Canadian Home Care Association has produced a report entitled "Integration through ICT for Home Care in Canada" [12] which notes amongst other things the imbalance in regard to ICT between the hospital sector and primary care/municipal care/home nursing. There is a realisation amongst decision-makers that an increasing amount of healthcare will be provided in or near the patient's home, but that it has not sufficiently influenced strategic decisions and resource allocation.

Although emergency treatment encompasses vital and important actions for the individual, it is the long-term relationship to healthcare which is of most importance to the many Canadians who are elderly or have chronic complaints. This relationship is built in the first instance with primary care and municipal health and social care and the public has high expectations of its medical care system. It is expected that information will follow the patient when different healthcare providers are utilised, that integrity will be protected, that opportunities to influence decisions will be given, that security will be guaranteed and that information and notification of results will be rapid. A flexible and complete integration of different healthcare services dominates the current healthcare agenda in Canada and ICT is regarded as an enabler of this. Research indicates ICT to be a crucial factor in making team communication, renewal and collaboration work.

In recent years, Michael Porter, one of the leading researchers in market development has devoted himself to studying American healthcare [18]. Amongst other things, he maintains that it is good to make continual improvements but that this is not sufficient in dealing with structural problems. Furthermore, he claims that today's competition has no connection to value creation and that healthcare reform must be based on the assumption that it will result in this. The objective must be to create patient value and not primarily a reduction in costs. Furthermore, healthcare must be organised around medical conditions and encompass the entire instance of care. Remuneration systems must be renewed so that value creation becomes profitable, considers Porter.

There are very many medical care systems in the US. A group of researchers led by Prof. Paul Batalden studied 20 of the best performing systems in order to understand why they were so successful in creating value for the patients. The study was aimed at the smallest medical care units in which healthcare personnel meet patients. The successful clinical microsystems (as they are known) are characterised by the presence of such things as competent leadership, a strong patient focus, an "information-packed" environment and a strong value-based culture. They work with systematic improvements to increase their knowledge of the results they have achieved and to develop their processes. The results of the study were presented to the Joint Commission Journal on Quality Improvement during the period September 2002 October 2003 and in articles by Batalden and others [19]. Microsystem has become a concept and a model for high-performing, value-creating healthcare and has spread to some degree in the US and Europe with its active participants including Jönköping County Council. The concepts we want to design in VVP harmonise well with the principles upon which these high-performing microsystems are based. For this reason, we will return to clinical microsystems later, particularly the dimension affecting information management (see sections 7.3-7.4)

In general, the Nordic countries are seeing similar challenges to the rest of the Western world. For example, in its National IT Strategy Denmark has described the anticipated development and produced a vision of future medical care which should be high quality and resource-efficient. Amongst other things, this vision is characterised by the ability of patients and citizens to become increasingly involved and for the collaboration between different actors to be developed. The intention is for ICT to support the overall vision and not be an objective in itself. Denmark is probably the country which has come furthest in the wide introduction of municipal communications services in healthcare. Estimates indicate that during 2008 alone, over DKK 1 billion was saved by using ICT to send various types of messages [17].

This international view indicates that the policy documents drafted at national level in various countries are fairly concordant and suggests that healthcare as currently conducted cannot be expected to cope with future needs. This also applies to a number of Swedish documents such as the National IT Strategy [4], the Swedish Board of Health and Welfare's "Good Healthcare" [20] and so on.

As we see it, the most important trend is the fundamental change gradually taking place through patients and relatives becoming more informed and participating more in health and social care. The roles of the most important actors (health and social care personnel, patients and relatives) are changing and will form the basis of the new conditions which healthcare must work with and adapt to.

That also leads to a need for information systems and e-services to be developed so as to meet patients' and relatives' need for information. The development which has taken place on the Internet in the past five years has meant an increase in opportunities for various forms of interaction with and between users. Many people within health and social care want to use the Internet to seek information, exchange experiences with others who have similar problems and to collaborate and contribute to building knowledge. In her thesis, Ingela Josefsson demonstrates how people are using the Internet in new ways to create value in the management of their (chronic) conditions. [21]

Still, the greatest challenge lies not in drafting policy documents or outlining new visions but in finding effective ways of driving the work of change towards the new visions and preparing and implementing e-services to support that work.

For this reason, in the VVP project we have worked with end users and field users so as to describe how change management should be designed. We will return to this in section 8. Firstly we will use the following section to describe a healthcare concept, the basis of which includes a new patient role and which safeguards the patient's contribution to increase value creation. This concept presupposes access to information and new, enabling e-services. These are described in section 7.

6 Proposed new healthcare concept – a patient process that creates value

The perception of value is highly individual and a value-creating process can only be created through patient and relatives having real participation in healthcare and planning. This should be built into work routines, methods and procedures to avoid it becoming arbitrary and actor-dependent. The aim is to individualise healthcare, in other words initiate those actions which create value for the patient.

This requires an ability to discern what the patient sees and expresses as value-creating, as well as flexibility that facilitates continuous adaptation to changed priorities and new needs. In order for the responsible healthcare team to work in this way, an organisation and other prerequisites must be created which enable provision of this individually tailored, value-creating healthcare.

In this section, we will attempt to describe the healthcare concept that we designed in VVP. We are assuming the patient to be an elderly person with multiple illnesses and a long-standing relationship with health and social care who needs varying input from differing competences. Healthcare is often provided in the patient's home or in municipal social care.

In this context, it is important to define and understand the layout of the patient process for this particular category of patient and how it distinguishes itself from a more traditional, standardised process. We will also look at how what is implemented relates to value creation.

> The aim is not to be normative but to indicate opportunities to develop the operation. Each operation must find its forms and contribute to building knowledge which leads to sustainable health and social care – better value creation and a more efficient use of resources.

One of the bigger problems in health and social care today is that collaboration does not work, especially when multiple authorities are involved. Before getting into processes and methods, we will therefore look more closely at the organisational circumstances.

6.1 Organising for continuity, collaboration and efficient use of resources

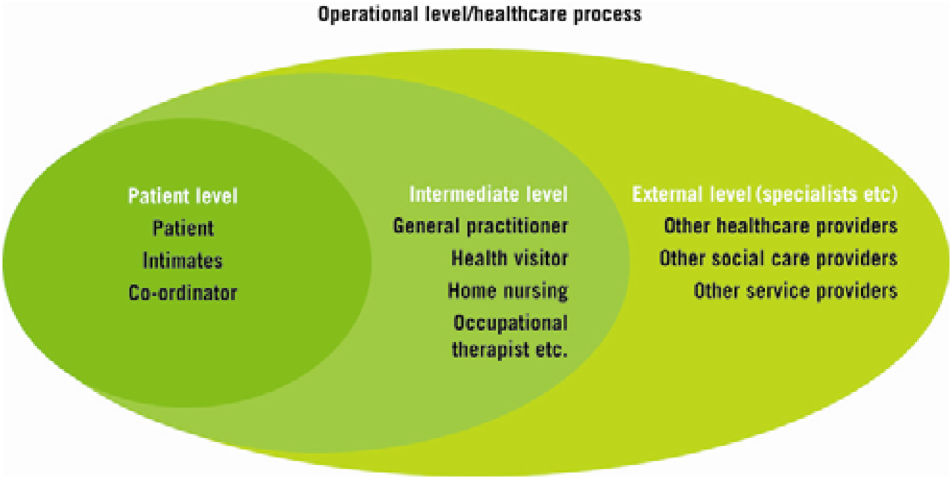
A major problem in today's health and social care is that patients come into contact with too many health and social care providers who have too many specialised duties.

When the flow of information also functions poorly, the patient experiences quality deficits and insecurity. At this point, we can actually say that value is destroyed, rather than created. Another consequence is that the likelihood of duplicated work increases. For this reason, health and social care must be organised so that continuity is as good as possible whilst safeguarding collaboration and good resource management. We have assumed that patients in our patient group need a team which can handle the vast majority of the health and social care they require. This team should be led by someone who has taken on the role of care coordinator.

The coordinators are in very close contact with the patient and occasionally also with some relatives. For things to function well, the coordinator must understand the patient including familiarity with their life history and what is important to them. They jointly form a "project management" with responsibility for discerning needs, formulating objectives, planning measures, allocating work and following up. They have at their disposal a project group with various competences. The composition of this group may vary over time, but it should comprise the competences/professions which elderly people frequently need. It is important for the team to be kept as small as possible and that there is continuity of contact. The team will probably comprise health and social care personnel with current affiliation to both municipalities and county councils. For this reason, municipalities and county councils should agree to collaborate on an overall plan and give the care coordinator the authority and resources required meet needs and create value in the best way. When needs cannot be met by the team, it will be necessary to turn to other providers by making "orders". General practitioners and Pharmacept are two vital competences whose contribution in terms of time is quite limited but which may be highly significant to the patient. Should their services be ordered or included in the team? We provide no answer to this; a good solution must be worked out.

By organising health and social care in such a way that the team or clinical microsystem deals with the greater proportion of health and social care needs, collaboration becomes less complex and demands for information management reduce. On the other hand, freedom of choice will probably increase the offering of different services, which implies a need for new information upon which to base decisions and recommendations. The figure below illustrates the different levels.

A change in the patient role is a central part of the paradigm shift. This has been our basis in designing the proposed care concept. Thus, e-services contributing to the patient's "empowerment" will become a vital component [24]. Equally important is changing the care provider role. The traditional role has been established over decades and is still largely supported in training and instruction.



From a service innovation perspective, the patient may be regarded as an underestimated and poorly utilised resource. If a person suffering with something is given the passive definition of "patient" during initial contact with those treating them, then their role is not far removed from what it was in the 18th Century. A "patient" was described, observed and treated ("acted upon") as a passive recipient of something from a service provider; a service provider who relieved the patient of suffering but took away their autonomy in return. Obviously, this is an unfair description as the entire scale is represented in healthcare, but it is true inasmuch as there is major development potential. Within other sectors, the role of "co-creator" is much more important for two reasons: Efficiency and risk minimisation. It is incredibly risky to develop services without a good understanding of what customers like and think. If the customer does not like the new service at all or only a little bit, then as a service provider there is a customer-relations problem.

6.2 What kind of patient process meets individual needs and creates the most value for the patient?

The knowledge gained in the project work combined with past experiences and knowledge from project participants has led to the vision of a new healthcare model which satisfies the new criteria for good healthcare that have grown up in recent years. We refer primarily to a new and more active patient role (including relatives) – healthcare which places a major emphasis on prevention and creates the greatest possible value to the patient. All this whilst being efficient and thus utilising available resources in the best way.

In the work of developing a new model for this target group, we have used (well-) known methods, theories and phenomena and combined them innovatively.

To create better organisational conditions, we have taken relatively large sections of the project model and modified it, designing and staffing the team in a flexible and individually tailored fashion – all to give the patient the best support and achieve established “project objectives”.

We have used a process-orientated approach to guide various efforts and activities, but we have also identified deficiencies in the traditional process models. As described in a previous section, there are essential differences between a *patient-orientated process and the patient’s process.* It is particularly important to consider this when the objective is the creation of value for the patient.

Objective formulation is critical in ensuring that the right things are done. It is also necessary to work iteratively to bring a dynamic into the process and avoid static objectives hindering the management of any fresh problems. In creating value for the patient, not only is it vital which objectives are established but how they are designed and by whom. By now, it is obvious that the patient and relatives should be involved and have as much influence as possible. This can only take place if the team personnel surrounding the patient work in what is known as a relationship-orientated fashion [22]. Various preventative efforts can also be introduced naturally into the concept which thus grows up.

Familiar quality assurance tools can subsequently be used to implement a new health and social care process (initially the PGSA wheel, but also fishbone diagrams, fourfold tables and value compasses). These tools are broadly established in healthcare but have mostly been used in organisational improvement measures and only exceptionally on an individual level. In the VVP concept, we want to try using quality assurance tools throughout, for increased value creation in individual health and social care planning.

6.3 Some thoughts on how project models and quality assurance tools might be applied to the individual patient process

In a good health and social care process/care planning or healthcare system, management and personnel work continuously to survey, analyse, discuss and reflect so as to improve their operation. Important areas for improvement are continuity, competence, access to the right care at the right time, approach and collaboration in order to achieve a flexible process for the patient.

The project model is being used to organise and guide the activities as development work progresses in most industries and social sectors. The project form is very often used in complex collaborations where different expertise from different organisational units must collaborate to achieve a common objective. Naturally, the principles upon which the project model is based are also used in different healthcare contexts, but not on patient level in direct healthcare work. They might also be adapted to organise healthcare for a patient with complex care needs. In the same way, quality assurance tools such as PGSA and the value compass can be used to draw up objectives, identify opportunities for improvement (in illnesses or conditions) plan measures and follow-up results for the individual patient.

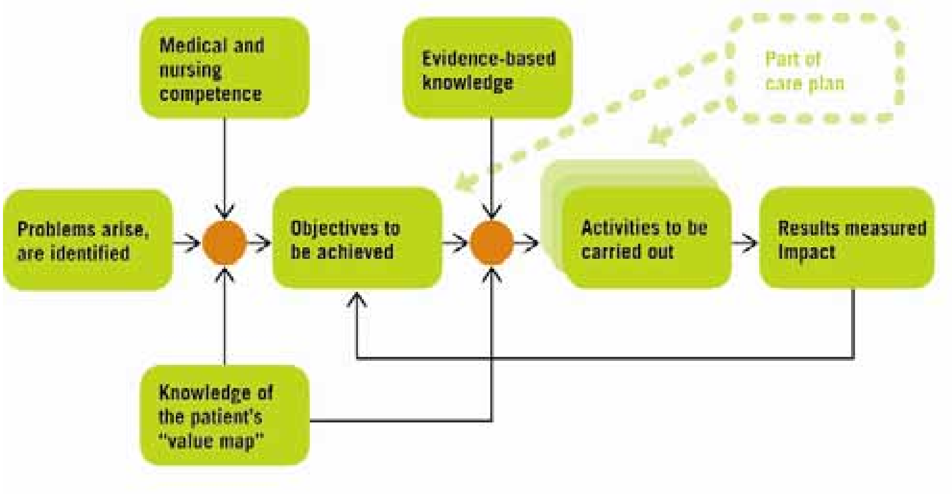
The advantage of project models and quality assurance tools is that they are well known, broadly accepted and widespread. Quality assurance tools are instructional and designed to create participation. They support learning and are easy to take on board. Using quality assurance tools in planning and implementing healthcare efforts should motivate patients and relatives to take a more active role and participate and be involved more. The opposite actually occurs when the profession talks “over the patient’s head”, reinforcing its advantage with incomprehensible technical language. Quality assurance tools also create structure and an overall view which increases involvement and the chances of everyone involved contributing and carrying out their obligations.

Somewhat simplified and adapted, the patient may be regarded as a project. The aim is to create as much value as possible during the lifetime of the “project”. This may take place by remedying problems which have arisen and by preventing them from arising (care prevention).

An operation can then be scoped in order to run a certain number of projects. The operation is responsible for identifying and starting new projects when justified. The project is started when a patient has “qualified” for it, for example when they reach a certain age or when the patient has such comprehensive health and social care needs that it becomes justified to start a project. Patients who might not be in immediate need but who are in the “risk zone” should also be included in the care model. By working proactively, it is possible to generate readiness and avoid being surprised by sudden changes in states of health which can easily turn chaotic. If healthcare cannot then cope with the situation, then the opposite of value creation arises; a common experience when visiting hospital A&E departments.

In their book “Dirigent saknas” [“The Absent Conductor”] [23] Gurner and Thorslund described how shortcomings in collaboration lead to elderly people faring badly. They seek a “conductor” – someone who can act as a project manager. In conjunction with the elderly person and, in the best cases a relative too, the “conductor” can act as “project management” for that case. They plan and determine improvements/objectives to achieve, what efforts should be initiated and who should carry them out.

All this should be managed in the care planning process. It is also crucial that the right efforts are initiated. Our attempts to describe this diagrammatically resulted in the following model. This builds upon results from the Intercare, Sams and MobiSams projects.



The planning needs to be dynamic. It should be possible to reformulate and modify objectives and set new ones. Objectives that are no longer important should be removed. There should always be the opportunity to amend the patient process when events occur that bring about new circumstances for providing health and social care.

For this reason, the model should be regarded as part of an iterative process. It may be appropriate to identify the most important areas of need and thereafter get into a more particular objective formulation stage. Input into the objective formulation process comes from assessment and observation, from professional competence and the patient’s value map. This should be interwoven with and influence the dialogue that leads towards objectives. This is where the patient’s value map is important. It gives direction and states what is important and what is less so. By finding out what the patient values and involving them and their relatives in the planning, the “right” problems can be addressed. Naturally, this must be balanced with the professional knowledge which the care coordinator and other key people in the team can bring. Correctly identified objectives lead to improvements. The PGSA method can be used to systematise and structure each objective or improvement measure. When objectives have been properly formulated, it is then a matter of determining what efforts of various kinds need initiating – from various competences, from relatives and from the patient themselves. The choice of measures can also be influenced here by the patient's value map but naturally also by what evidence such as knowledge, science and trusted experience can add. The final stage in the model above and in PGSA is to measure and analyse the outcome and results of efforts made. Depending on the outcome, fresh decisions may be taken. Occasionally, the problem may be remedied, but in other cases knowledge may have been gained showing that the problem is actually slightly different and that a new objective needs formulating and new measures initiating.

6.4 Value creation as a basis to formulate individual objectives for the patient's health and social care

In the dialogue relating to which objectives should be set up, these are (directly or indirectly) related to the patient's "value map". This presupposes, or is naturally facilitated by, the continuity and close contact between patient and care coordinator. This work takes place continuously as new problems are detected but may of course also be carried out at certain fixed intervals if the care situation allows.

The use of PGSA creates structure and systematism in this work. Objectives become clear and are formulated in conjunction with the patient and relatives. It thus ensures that objectives will lead to something that brings value to the patient. It is also natural to involve the patient when choosing efforts and when it is time to follow-up whether the efforts/measures initiated really did lead to achievement of the objectives. The patient gains more opportunity to influence the planning. This is not to imply that all elderly people are able to exercise their influence, but this should be the ambition and aim.

Models consistent with this outlook include the Model for a Relationship-orientated Working Method [22] which was tested with good results in a number of operations including Region Västra Götaland.

6.5 Care planning which aims to achieve individually formulated objectives

In describing how it should be possible to design the patient process for elderly people, our foundation is that activities conducted in the process should create as much value as possible using available resources. Activities which do not create value should be avoided.

It is not possible to work out a strict correlation between an overall objective and evidence-based efforts for the patient group in question. Through various occurrences, a vibrant elderly person can rapidly become a frail patient with major healthcare needs. For these patients, it is expected that fresh problems will arise. New objectives are formulated and measures/activities planned. This means the team must be able to adapt rapidly to new efforts. Since the future is not predictable, especially not for these patients, the overall patient process should be the sum of a number of subsidiary processes, all with clear objectives formulated in consultation with the patient. This planning work is documented using a PGSA wheel (see example in section 8). When planning, decisions are taken as to what measures should be initiated; these choices are also important to value creation. A number of activities may be regarded as very negative by the patient, whilst others have a much more positive experience. The patient and relatives can therefore participate naturally in the planning work and have influence over the choice of measures as well as who carries them out.

There will be more wheels as the work progresses. Occasionally, in order to achieve objectives, it is necessary to use standardised/evidence-based subsidiary processes. The care plans which are produced may be partially grounded in evidence-based knowledge, something which is aimed for and can be gradually expanded. E-services which support and facilitate the use of evidence-based efforts will be important in bringing quality to the work.

Naturally, it is possible to envisage many different preventative efforts and that priorities may need to be laid down. In the planning work, particularly if many efforts are required, quality assurance tools such as fourfold tables and fishbone diagrams may be used to create structure and support prioritisations.

Another consequence of the above argument is that what is valuable to one patient may not necessarily be so for another. Care plans can and should be based on some form of healthcare programme – with an evidence-base if possible. However, this must always be individualised by checking it against the individual patient's appraisals and perceptions of what creates value.

There is much knowledge to be gained from Jönköping County Council which, amongst other accolades, received the 2008 Golden Scalpel award for care prevention focusing on pressure sores, falls and nutrition. The bases of care prevention are:

- Building in prevention as a priority effort.
- Identifying risks such as fall injuries, nutrition, pressure sores, side-effects and interactions.
- Identifying risk patients who require special attention.

6.6 Quality assurance tools such as PGSA and the value compass in support of patient work

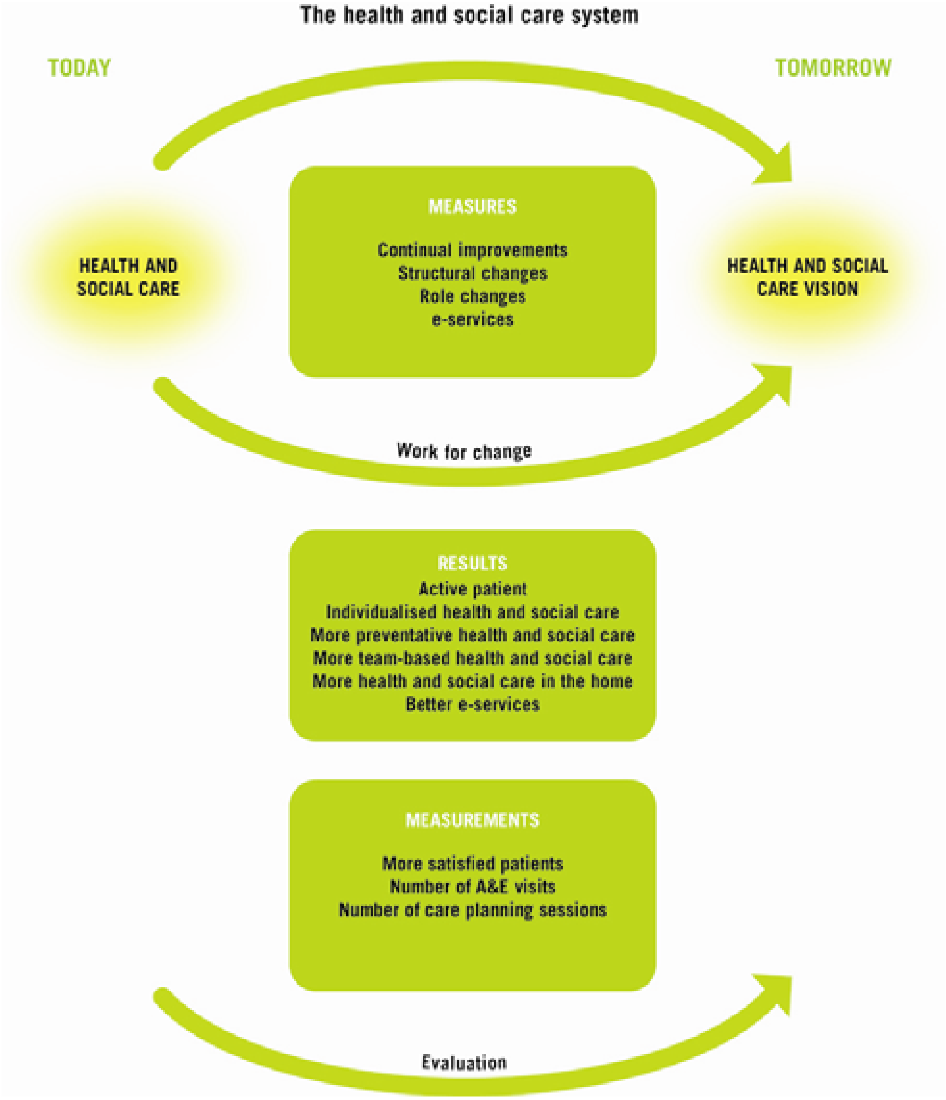
Once objectives have been set, plans are laid as to which activities need to be brought in. This is where the PGSA wheel comes in handy. At this level, it should (at least for some problems) be possible to standardise or evidence-base efforts. In a working model such as this, the patient will have major influence. For the huge majority of elderly or vulnerable patients, it is possible to discuss their situation starting with symptoms, problems, objectives and possible efforts. Obviously, the patient's own capacity should be taken into account as much as possible in the planning.

The model may also be used for preventative/precautionary purposes. This is important, since events often occur which have strongly negative and occasionally disastrous consequences. It is worth assessing the risk of such events occurring and taking measures to avoid them. Examples of such events are injuries from falls, infections, varicose ulcers, drug side-effects, dehydration/malnutrition etc.

Converted into everyday activities, this means: intensified interaction across disciplinary and hierarchical boundaries; the patient participating in value creation; mutual learning between health and social care personnel and the patient; increased teamwork in which clear working boundaries are reduced, benefitting the joint potential created in the collective intellect; and a service perspective (i.e. the patient's needs and wishes being put before those of the organisation).

As a patient or relative, working (in a team) alongside healthcare personnel should create a greater totality, better continuity, increased assurance and participation. There are indicators (which naturally enough need more thorough investigation) that the total time spent on medical care and the patient would reduce and lead times shorten significantly if such a perspective and working method were to be introduced. Misunderstandings could be minimised and thus also incorrect treatment, unnecessary suffering and complaints. Such an approach would also have the potential to make decision-making faster and more reliable. However, another set of assumptions is required to reshape healthcare towards increased focus on value creation for the patient. The "healthcare machine" can't go any faster because it isn't a machine!

The transformation to a new care concept is clearly illustrated in the figure below. Various measures need to be initiated so as to realise the vision. A successful transformation leads to results which are encompassed by and typify the healthcare vision. There is continuous evaluation of results achieved to ensure that the change management is giving the desired results. When change management commences, it is important to fix the healthcare vision into measurable results, explaining which results are relevant and how the measurements should be conducted.



In the next section, the challenge for VVP is to describe e-services which meet the new requirements and then describe how implementation should proceed.

7 e-services

7.1 Introduction

In the previous section, we outlined a new healthcare concept. Realising the visions requires comprehensive change management and ICT and e-services form an important part of this. They may be directly necessary in order to create the information supply required by a changed working method requires or if the patient’s role is to be renewed towards that of an informed, participative and co-determining patient [24].

There is broad consensus that ICT and e-services are a strategically important resource in realising the new healthcare visions. The existing IT systems are not meeting the requirements of modern operations and will cope to an even lesser degree with the requirements of the new healthcare concepts.

IT departments have long had power over IT investment, and still do. Many different considerations must be borne in mind – finance, security, functionality etc. There are not enough resources to go around and operating and maintaining existing systems means there is very limited space remaining to develop and try new things. This is particularly bothersome in a time when radical new requirements are rapidly emerging.

Most municipalities and county councils are in the hands of the major IT suppliers who are consistently striving to consolidate their positions. There are many examples of costly system roll-outs and dissatisfied users and several major investments have failed completely. There are exceptions and in all fairness, mention should be made of the in-house development which took place in Norrbotten. Users of the VAS case record system are satisfied and it appears that an information supply has been created which is up to standard. Jämtland and Halland have opted to introduce the concept and share ongoing development costs.

New national investments are also being made now which are regarded by many as high-risk projects. If the investment in the National Patient Summary succeeds from a purely technical standpoint, then it remains to be shown whether the services are generating the benefit that means they will get used.

A prerequisite of collaboration is that the information supply should be sufficient for collaborators to have access to relevant, common information. There are major deficiencies here in that existing systems are not built for communication. True, technological developments have made it simpler to exchange information between systems using so-called WebServices, but essentially there is no well-reasoned collaborative architecture. It may be that systems which are poor at communicating with others can become a little less poor. A number of new e-services have been developed to support the coordinated healthcare planning in conjunction with patients being discharged from inpatient care. These meet A&E requirements, but in most cases are inadequate since many patients require ongoing, coordinated care planning.

7.2 What pattern can we see?

Many are of the view that a radical new design is required. This is further underlined by the new challenge meaning that patients themselves will be more informed, active and participative. The existing health and social care system has been developed to meet the needs of different care providers and the patient has not been deemed a stakeholder in this context. In that regard, a manifest fluctuation is discernable and awareness of the need for new e-services and systems has gradually increased. Medical advice and “healthcare on the Web” has made a major contribution to opening up new opportunities. The new challenge is to make the information accessible and tailored for the general public and patients so that they can take increased responsibility for preventative, curative and rehabilitative efforts.

We can distinguish two strategies for meeting e-service requirements for patients with complex needs and involving different units. One has been to carry out coordinated health and social care planning and develop the interface between the various care providers’ existing systems so that they can be updated and potentially update joint functions. This means no new structures are created but existing channels become fixed. This strategy gives little or no support at all to patients and relatives in their roles. The other strategy which has become established in recent years comes from the US and deals with creation of patient case notes. The patient then “owns” their information and gives authority to view its contents to those they consider should have it. Major interests such as Google and Microsoft have launched products based on this strategy. The idea is that it will be possible to automatically export information from computerised case record systems and update personal case notes. The patient owns their information and determines who can access it. The solutions are based on the fact that the services exist on the Internet and that it should be easy to subscribe to the service. It should be secure and intuitive. However, there are a great many questions relating to patient integrity etc.

The development we can see is not unique to health and social care about is entirely in line with and probably largely a direct consequence of more general trends and phenomena in other sectors and in society as a whole. The underlying philosophies of Web2.0 harmonises well with the visions of new healthcare concepts we described earlier and which the clinical microsystems represent.

Webb 2.0 changes the roles between customer and supplier, making them less clear-cut than previously. Customers become co-producers (crowd-sourcing) and participate in problem-solving (crowd-power). New business models grow up and new infrastructures create new conditions for the development and operation of e-services. Software as a Service (SaaS) is a concept which exemplifies this. Naturally, Open Source, i.e. freely accessible software which can be further developed by users and companies, must be viewed and managed in this context. Cloud Computing is another phenomenon which is beginning to take shape. This will mean radical new circumstances for offering e-services and running IT systems. Despite these phenomena having been around for some years now, we are very much at the start of something whose full scope we cannot yet see. If Webb1.0 was about information then Web2.0 is about collaboration, networks and society.

So, has all the past work relating to the development of data models, information models, standards and so on been wasted? No, we don’t think so, but we must take on board the new conditions and opportunities. Domain knowledge may be crucial in the development of e-services that create value. At the end of the previous section, we put it like this:

“It is incredibly risky to develop services without a good understanding of what customers like and think. If the customer does not like the new service at all or only a little bit, then as a service provider there is a customer-relations problem…” Naturally this applies largely to e-services as well.

7.3 Strategy for VVP

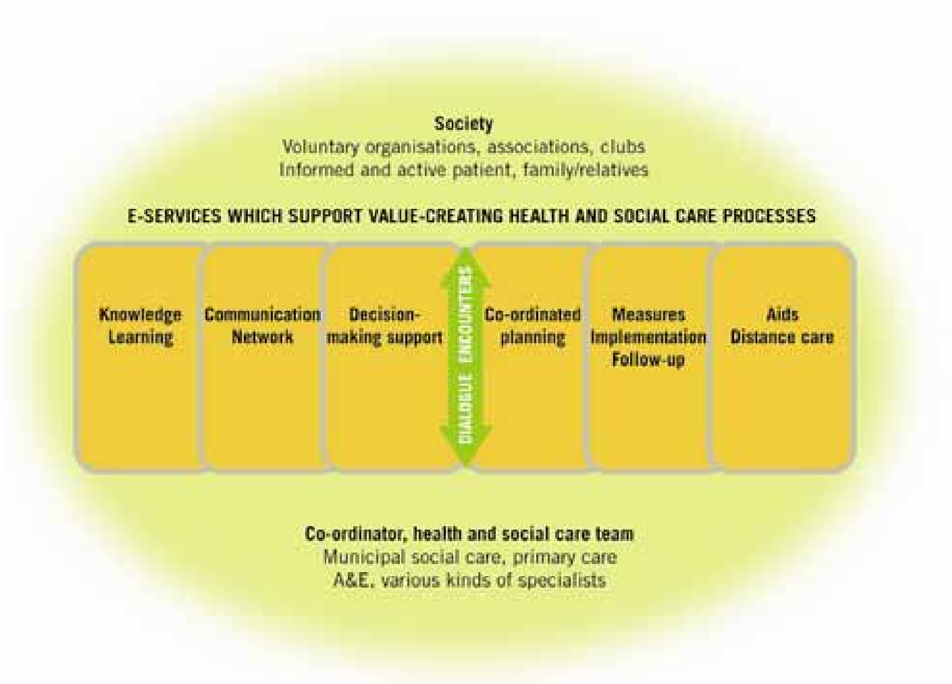
None of the strategies that have been described meet the information needs of the VVP concept. In VVP, we advocate a *third strategy* which is a consequence of the design of the care concept. The VVP strategy means that we organise the operation in clinical microsystems around patients and relatives. The old channels are being broken down. The patient is part of the team, meaning that the roles of patient and healthcare personnel are changing and that information is becoming a common resource. As long as the patient is in their “microsystem” then, in principle, information need not be anywhere else. In the case record systems of primary care and hospitals, it is enough to enter that e-services may be called up and information retrieved if doctors and nurses are authorised. When a patient visits primary care, it should be possible for this to be included and planned via the ongoing care plan and thereby documented in the team’s dedicated e-service. When a patient visits A&E or is admitted to hospital, the information systems there are used and the exchange of certain structured information (such as discharge notes) can be carried out between systems.

In the theoretical development surrounding clinical microsystems [19] the information supply is included as a central component and the message to those who can influence the situation is:

“Contribute to the creation of an information-rich environment for patients and staff.”

- The success of the clinical microsystem depends on the interaction between patients and personnel. Those who are included must be linked together in a positive and productive way so that the right things are done in the right way and at the right time.
- Give everyone the right information at the right time to do the job.
- Utilise IT support fully to back up the health and social care work.
- Listen to everyone’s ideas and link them together thus benefitting patients and actions in support of the patient work.
- Offer more channels for patients to integrate with the microsystem. They should be able to contribute information to the microsystem and receive information from it (e.g. in writing and by telephone, e-mail, web-based information and group visits).

The following diagram illustrates how dialogue and interactions between health and social care personnel, relatives and patients can be supported by different categories of e-services.



Source: Linda Askenäs, Bridging the Gap

The rapid development taking place on the Internet is primarily being driven by young people. There are clear generational divides in which elderly people generally use the Internet to search for information and make certain payments, if they use it at all.

For teenagers, the Internet is completely natural; they more or less live online and cultivate most of their social contacts via the Net. Within healthcare, we can see that those operations working with children and young people are one step ahead in their Internet use. We are convinced that elderly people too – albeit not the most elderly – will use Internet services to learn, exchange experiences and communicate with children and grandchildren, friends and relatives. The huge majority of these services are entirely beyond the control of health and social care whilst others might perhaps be organised in portals run by official actors.

A good example of how the technical opportunities have been used creatively to bridge obstacles for novice computer users is the VINNOVA-supported project, IPPI. This uses the TV as an interface to communicate and interact. The information involved can be anything from a video dialogue to SMS/mail communication with the medical clinic.

In a VVP context, the strategy should be to successively develop an approach so that all these services can gradually support and take on board things that create value.

7.4 e-services supporting collaboration, communication and learning

Information guides intelligent action. A lack of information hinders the opportunity for smart action. The following processes support this important principle:

- Designing and organising a working environment which gives access to a lot of information that supports and informs day-to-day work and strengths important competences needed for good health and social care.
- Creating a number of formal and informal communication channels to inform and involve everyone included in a microsystem – patients, relatives, personnel – information within a reasonable time.

There is much discussion of the need for different systems to be able to communicate with each other and the shortcomings of existing systems. The integration solutions which must be carried out in the existing environment may indeed be facilitative and rational, but tend at the same time to cement existing structures and processes.

The need for communication also depends on how healthcare is organised. The healthcare concept we are drafting in VVP will involve a reduced need for communication between different healthcare systems as the common, ongoing care planning takes place in the team where everybody has access to the information that is generated and required. The need for costly integration solutions diminishes.

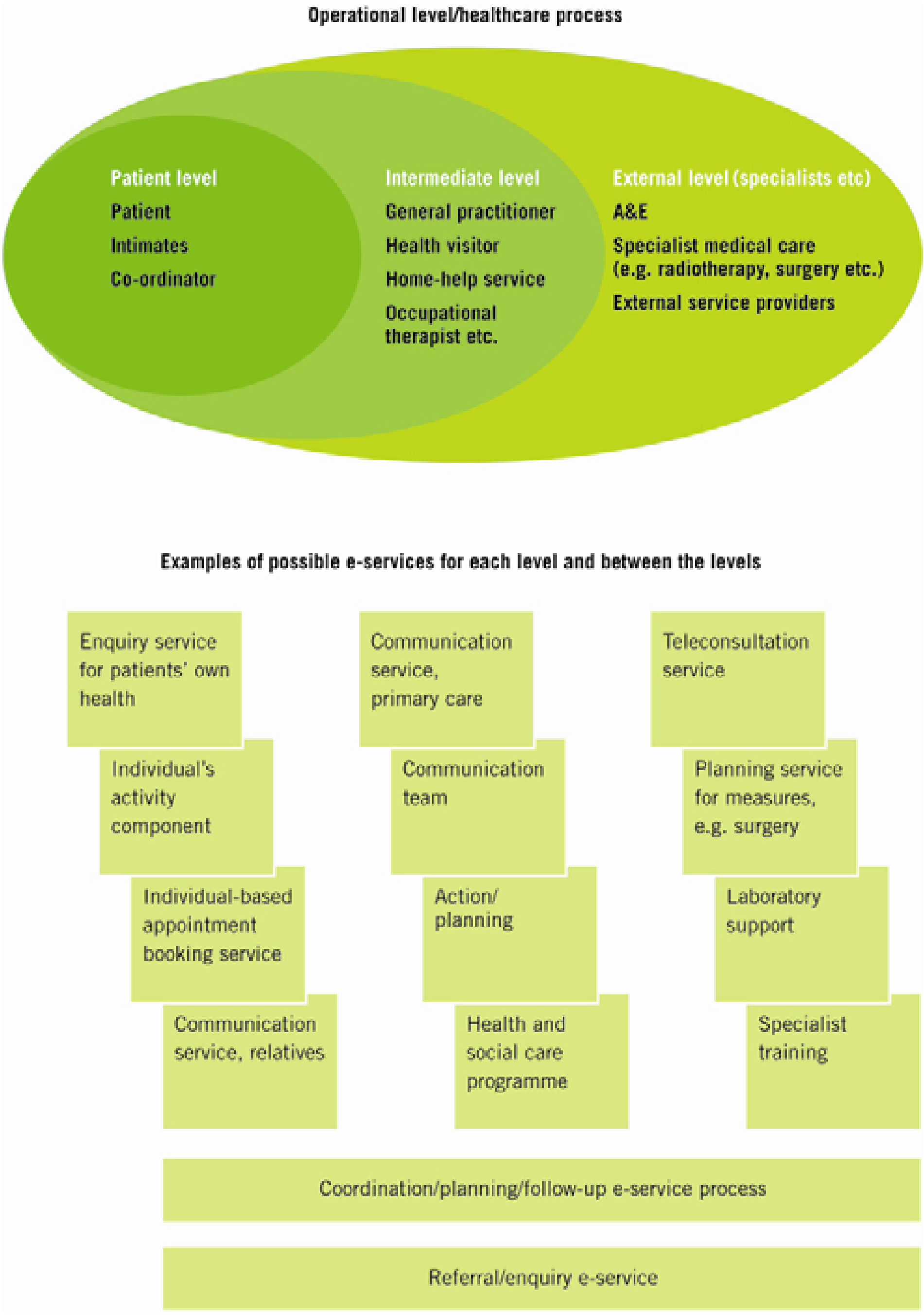
It is the microsystem's collaboration with the outside world (i.e. other care providers and service providers) that requires communication such as reporting to various interested parties. A more component-based, service-orientated architecture (SOA) would increase flexibility. Aided by WebServices technology, it is relatively simple and cost-effective to create the necessary loosely coupled interfaces.

The most important, value-creating e-services for clinical microsystems can be grouped into four larger clusters:

- Services which support the ongoing health and social care planning, care documentation and follow-up.
- Services which support communication and ordering of services etc. from outside and which can be extended in pace with the local professional/social network.
- Services which make it possible to seek various kinds of web content and which create an opportunity to build networks/communities. This may also include games and entertainment.
- Services/mechanisms which make it possible to integrate various telecare aids and sensors which may be necessary to ensure safe healthcare in the home. Various devices for remote monitoring are constantly in development. The majority of these have their own communications solutions and databases but in the long run it will be untenable to have all these autonomous systems. Information that is generated must be integrated into the team's common platform so that it becomes a part of the overall information and documentation.

It is a case of creating the basic services to give the greatest benefit and support a new concept in the best way. Because these services are, by their nature, more independent and can be combined in different ways, there is more opportunity to take on board functionality as the operation reaches readiness. The new e-services should also be characterised by innovative graphic interfaces so that items such as quality assurance tools can be integrated. Clear menus and navigation will be other attributes enabling users to choose e-services and find that they are value-creating an entirely different way to traditional systems.

The following diagram illustrates how different e-services can support the operation and different actors of the VVP concept.


Operational level/healthcare process
Patient level
Patient
Intimates
Co-ordinator
Intermediate level
General practitioner
Health visitor
Home-help service
Occupational therapist etc.
External level (specialists etc)
A&E
Specialist medical care (e.g. radiotherapy, surgery etc.)
External service providers
Examples of possible e-services for each level and between the levels
Enquiry service for patients' own health
Individual's activity component
Individual-based appointment booking service
Communication service, relatives
Communication service, primary care
Communication team
Action/ planning
Health and social care programme
Teleconsultation service
Planning service for measures, e.g. surgery
Laboratory support
Specialist training
Coordination/planning/follow-up e-service process
Referral/enquiry e-service

7.5 Processes, collaboration, operational services and requirements for e-services

By way of introduction, we made the following assumptions:
Computerised information services will be an important element in changing health and social care towards more process-orientated and collaborative working methods centred on the individual's requirements and value creation. This creates a requirement for e-services to be more communicative so as to support the individual's entire process (the patient process). Such implemented e-services are largely absent today [30].

As this chapter continues, we will primarily review the conditions for dealing with this and concentrate on mutual care planning, follow-up of various activities and requisitioning of complementary services (services over and above those the individual team can supply).

Services can be limited to operational levels:

- One example might be analysing a blood sample and reporting the results to the actor who wanted the analysis carried out. The analysis is needed in order to determine what action should be initiated.
- Another example might be a consultation in which a general practitioner consults a specialist in order to set a diagnosis.
- It might also be possible for a patient to become a provider, by doing certain exercises twice a day for two months and reporting their mobility status in a set way.

As there are many actors/implementers supplying different services, services on the operational level must be defined and described so that the intended results of the process can be achieved. The Health Services project supported by VINNOVA (see www.VINNOVA.se for more information) has studied the service concept more closely. It has also described how, say, a department can describe and publish an "offering" of services to the outside world.

The implementation of a service means that an actor is carrying out a number of actions in order to achieve a given result. It is important that the anticipated results of the service are well described as the provider must often choose how measures are arranged to achieve a given result. The department providing a service may also collaborate with other units whilst the service is being provided. In this case, a number of other activities need to be carried out in order to achieve the overall desired results.

If services on the operational level are to be provided effectively, then there needs to be a good information supply. In an information and service society, information may be considered a "raw material". E-services should be designed and demarcated so that they are consistent with the structure of the various services on the operational level. This is part of the work of designing an overall architecture.

The e-service should provide sound support for the operational service. It should also be possible for the e-service supporting the operational service to communicate with other e-services. These deal with the information given when requesting the operational service, and supply information and other results from the operational service in regard to what has been achieved.

Some e-services are aimed at supporting a given operational service; others are aimed at supporting the discovery, selection and initiation of an operational service from another healthcare provider.

An example of the latter is a referral and response service. This means that the e-services can normally support the discovery of an operational service to suit a given need in the process, as well as identifying units which could carry out a given type of service. Moreover, the service may also support the framing of a problem and highlight relevant information required by the recipient in order to carry out the operational service whilst serving as a monitoring service so that involved actors can see the status of the referral (whether it has been read, allocated to those making assessments etc.).

Another example may be e-services supporting the initiation, planning and implementation of a given operational service within health and social care. This means that the e-service supports: description of the activities to be carried out; allocation and planning of how they should be carried out; and follow-up of which activities actually have been carried out and their results etc.

The design of the process sets standards for the content of the operational services as well as the properties of the e-services.

The care plan is an important instrument for keeping together the patient’s process, objectives which have been formulated and the various activities which different actors must carry out, plus follow-up of these linked to the objective of the plan. The operational services should also include management of these health and social care plans so that they are up to date and relevant. This enables corresponding e-services to describe the plans in terms of content and how they fit together.

In the previous section, we proposed that quality assurance tools such as PGSA should be used in health and social care planning. If this is done, then naturally there is a call for e-services to be designed to support such a working method. It should be possible for objectives, actions and follow-up to be documented in ways that make it easy for users to familiarise themselves with what has been planned, what has been done and what results have been achieved and to create new PGSA circles.

If there is a choice between different e-services with similar functions, then it may be difficult to choose the best from among different suppliers. An operation may have difficulty managing this and so it may be practical for a supplier to offer a cluster of services which work well together and thus create more value than they do individually. An example of such a cluster is the “care planning cluster”. Such a cluster consists of an overarching service such as “planning”. Services which might be included in the “care planning cluster” would be “actions” and its selection; “resources”, such as funds and individuals; and services such as “follow-up” and “timebook”.

7.6 How can e-services be developed which support operational processes and create value?

There is fairly widespread criticism that IT systems do not create the anticipated business benefits and that systems cement old structures when instead IT and e-services should be contributing to renewal. The feeling is that the system development is technology-driven when it really should be operation-driven. In VVP, our starting point has been an operational development with a strong emphasis on increasing value-creation for patients. The analysis is based on the desire to achieve health and social care that focuses on the overall needs of the individual. When new roles, new processes and new working methods are being designed, it is often held that e-services can be an enabler in successfully changing health and social care. An example might be the new patient role which requires entirely different information then has been available in traditional systems. Increased participation and co-determination requires access to information. In VVP, we have produced the Patient component [31], Which satisfies these needs. Other information and e-services which create new opportunities are being produced by the Swedish Healthcare Advisory Organisation whilst yet other sources of information are being created by entirely new actors.

The more traditional planning and documentation systems in health and social care need expanding with a more integrated approach, and this requires:

- Interest on the part of professional health and social care providers in focusing on the overall needs of the individual and that e-services based on this can offer information support.
- Ease of identifying principal needs so as to formulate the overall objective and work towards it.
- Gaining an overall view of the individual’s needs and what is planned for them. This fosters a realisation that measures must be coordinated in order to generate the greatest value for the patient.

- Access to information about all planned and implemented actions in order to follow up success levels in meeting overall needs and whether the measures taken were successful in achieving the desired results.

E-services which support a more process-orientated approach, support collaboration and are centred on the needs of the individual need to communicate with each other more effectively. One consequence of this approach is that future e-services will be smaller and less interlinked with major “systems”.

If the intention is to build health and social care that creates value for the individual then the processes and sub-processes needed to create it can be defined as we manage change. Once the processes are defined, the workflows to realise the values can be defined.

The first step is to define the process stages required to build the identified values. However, there should initially be an identification of which values are to be extended from the individual’s point of view. Such values might be:

- Avoiding illness.
- Answers to questions about the individual’s health issues.
- Answers to questions about what health problem has been found.
- Clarification and consensus about what we should do.
- Perceived improvement in condition for the individual.

7.7 Architecture and standards for e-services

In complex organisations such as the health service, information systems must be organised according to a comprehensive model. Historically, these models have been created by the bigger suppliers. This led to closed systems with little flexibility. Systems became an obstacle to change. As the operational circumstances changed, so demand increased for a system and ICT services that could support and not hinder the new operational concept.

When we have worked with process orientation and continuous improvement in the operation, the old systems have not kept up.

Despite this, there are great hopes as to what ICT can do for healthcare. Major investments have been made despite the failure of many IT projects. There is an awareness of the risks of technology-driven projects, but despite this new ones are starting all the time.

Within industry, the Enterprise Architecture Planning has been a process striving to design IT support so that it effectively assists the work of achieving operational goals. From this, the development of service-orientated architecture (SOA) has grown up. A technology which has had a major influence on the growth of SOA is Web Services which make it possible to get systems and components to collaborate (interoperability) and which facilitates the link between technology and business processes. Organisations, including the health service, are continuously changing and there are ever-increasing demands for this to happen quickly and efficiently; this in turn places demands on the architecture of information systems. With the opportunities afforded by SOA, so the chances increase of creating the necessary flexibility to meet the new needs resulting from process-orientation and new healthcare concepts. Earlier, we described a number of e-services which may be included in a common architecture. We have only made an initial definition of this structure in the project and there needs to be further clarification.

This flexibility and opportunity to reuse services by combining them in new ways harmonises well with the dominant approach to change management in healthcare – breakthroughs and continuous improvements. The concept used for this type of system development is called Agile Development. Another consequence of the service-orientated architectures is that the approach can then be how IT systems should be built, demarcated and interact based on the operational perspective, but without foregoing effective technical solutions.

A further aspect of the information supply should be given brief mention. In order for information to be exchanged between systems and understood by users, different standards have had to be developed. This has gone on for decades and much remains to be done.

There are standards on different levels. Each standard should be used on the level where they create benefit for the individual and the patient. For example, the standards within health and social care which must be addressed are on message conveyance level, such as openEHR, HISA and HL7. These types of standards should be used as reference architectures. There are also other challenges when it concerns standards. Creating connectable e-services which support the individual's overall process is something which has not yet been given adequate focus in the current standardisation work.

Examples of this are the standards mentioned in many contexts which have come into use in a number of quarters in the European environment, such as openEHR and EHRcom. These standards are based on the classic case records systems and can be said to have major limitations from a process-orientated point of view. So far, the standardisation work has been designed in groups "around a desk". Additional standards are therefore needed in order to support the individual's entire process, i.e. the overarching information required to support the individual's process within collaborating health and social care. Developing process-orientated standards requires "an operational field" for testing and verification. Results from this operational field can be used to contribute to the work of the standardisation body in preparing new standards, i.e. the fieldwork describes and gives input to the “new process-orientated standardisation work”. Verifying the benefits on the basis of patient needs requires fieldwork to analyse the impacts of the models described, i.e. that they are usable! The models need gradual verification and refinement as they are developed in a cumulative process and implemented in the operation. Thus, opportunities increase for the created standard to be accepted and used.

We have a tradition of local modelling which has led to many variations on the same theme. This has added up to a comprehensive initiative and many times has resulted in models when there has been no capacity or opportunity to convert them into usable systems. Many consultants have done well over the years, but not much operational benefit has been generated.

When the National IT Strategy for health and social care was finally laid down, it also covered activities for designing common terms and standards. The National Information Structure project (NI) has worked on production of a process-orientated information structure. A generic process model of health and social care has been developed as a first step in the NI project. The NI project is based on the objectives described under Good Healthcare [20] as intended by the legislators and in the objectives formulated under the National IT Strategy for health and social care [4]. The project is based on an integrated view of the health and social care process. It should be possible for information required in the process to be discovered, made available, be usable and be communicated regardless of organisational and geographical boundaries. The delivery of the NI project is three generic models – a process model, concept model and information model and a description of how these should be used to facilitate “health and social care documentation that is fit for purpose”.

8 Implementation

8.1 How can new care models/concepts and new e-services be best introduced?

The initial difficulty lies not in creating new visions for designing new e-services; the challenge is introducing them and using them to create value for the patients.

In the introduction to this section, we describe a use case/scenario which will hopefully provide further concretisation of the healthcare concept. We provide examples of methods, tools and ways of working which have proved useful and effective in systematic operational development in health and social care. We hope they may be a source of inspiration in local change management without being normative. The description does not claim to be complete; it is only an example and requires ongoing development and adaptation.

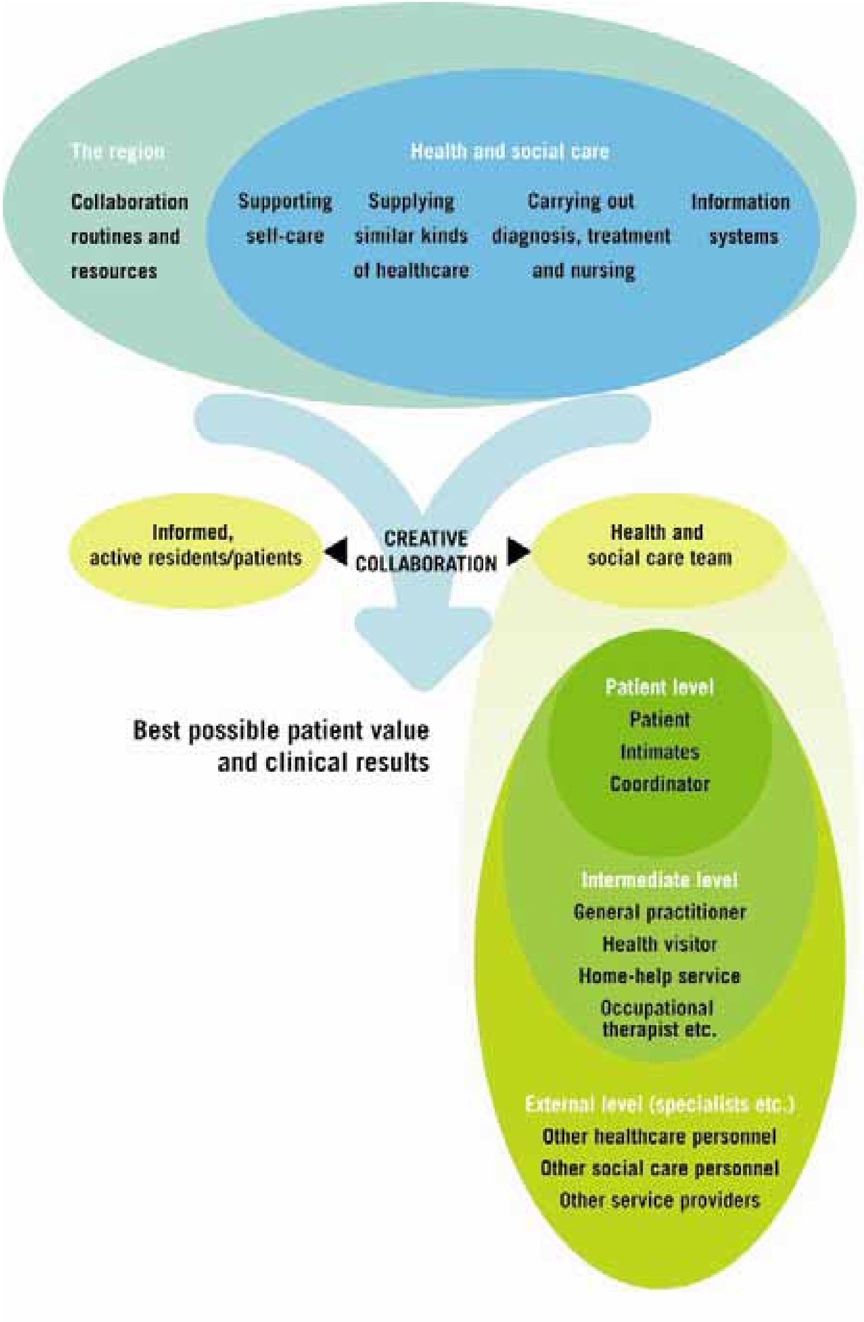
There is then an outline of an introduction strategy and a paper emphasising the importance of leadership in creating the conditions required to realise the vision of better health and social care.

When new concepts are to be introduced which go against ingrained patterns of thinking and working, it is particularly important to measure outcomes and create new incentive models and reimbursement systems which motivate and inspire.

E-services were dealt with in section 7, but a discussion of how these may be adopted into use is the focus of this chapter.

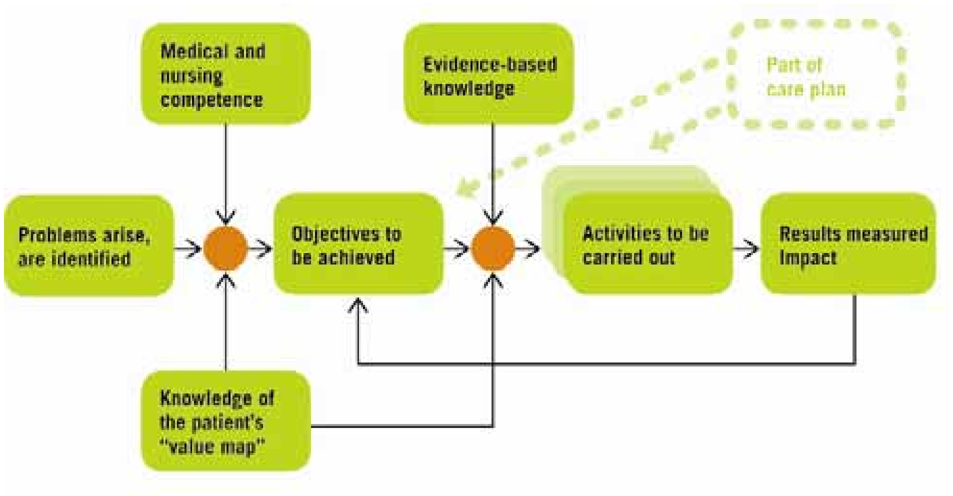
According to Wagner's Chronic Care Model 2001 [26], changes on many levels are required where experienced and prepared care teams create collaboration with informed residents/patients.

The composition of the team can and should vary in size and competence depending on the health and social care needs of the patient. The diagram is a variation of Wagner's Chronic Care Model.



Source: Wagner, Chronic Care Model

The team’s healthcare planning process follows the model we presented in section 6:



This should be viewed as an iterative process in which new observations and knowledge constantly influence the planning. New areas of need may arise and others may cease or lose priority as a result of earlier initiatives.

We will now convert the model into a use case based on reality and then follow a description of how it should be possible to shape the organisational conditions.

8.2 Use case/scenario

Karin Persson is 86 and has been a widow for some years. She was born and grew up in a fairly small village where she has worked all her life. Her children and grandchildren are nearby and her greatest wish is to be able to live in her house despite this now being too difficult for her.

The municipality and primary care have introduced a new collaboration model and, due to her advanced age, Karin has been given a *care coordinator* – a nurse employed by the municipality with the authority to create and lead a *care team*. The care team is intended to serve Karin’s medical needs as well as her nursing and rehabilitation needs.

So far, her care needs have been limited so no health team has been formed to provide Karin’s health and social care. After a couple of years’ wait, Karin has finally had her knee operation. The rehabilitation plan was drawn up in the same week she was admitted for surgery. Upon returning home, she received an exercise programme to rehabilitate her hand. She is still in pain and must use a rollator.

The care coordinator’s first action is to visit Karin at the geriatric care unit. Having had regular contact for some while, they know each other well and the care coordinator has a good idea of what Karin appreciates and finds important. Karin’s medical treatment is complete and she is ready to come home. It is now apparent that Karin needs a lot of health and social care and that this should take place in her home.

The care coordinator establishes the team with important actors who meet with Karin and her relatives at her home in order to jointly work out a care plan. This care plan includes such things as a needs and risk assessment. An individual health and social care plan is worked out which now covers seven areas of need. These are each planned, systematised and structured using one or more PGSA wheels and a value compass.

Needs profile and overall actions as a basis for a health and social care plan:

1. Difficulty moving following a knee replacement, right knee.
2. Pain in right knee due to knee replacement.
3. Risk of falling.
4. Reduced appetite.
5. Difficulty with personal hygiene.
6. Social isolation, feelings of loneliness and depression.
7. Lack of coordinated drug prescriptions.

Problems are described and objectives formulated for each area of need in the relevant health and social care plan. A responsible person is appointed and a timetable for each activity determined. The care coordinator gives feedback and makes the team aware of results. Using PGSA and the value compass ensures that health and social care is followed up from different functional, medical, nursing and satisfaction perspectives as well as cost.

The care coordinator coordinates the health and social care even when it is interorganisational and makes the necessary contacts as required. The care coordinator leads planning of the various efforts taking place in consultation with the patient/user, relatives and those in the team contributing competence and experience. The patients and relatives participate in the care planning. The right competence, continuity, access and approach are other important keys to generating value-creating health and social care.

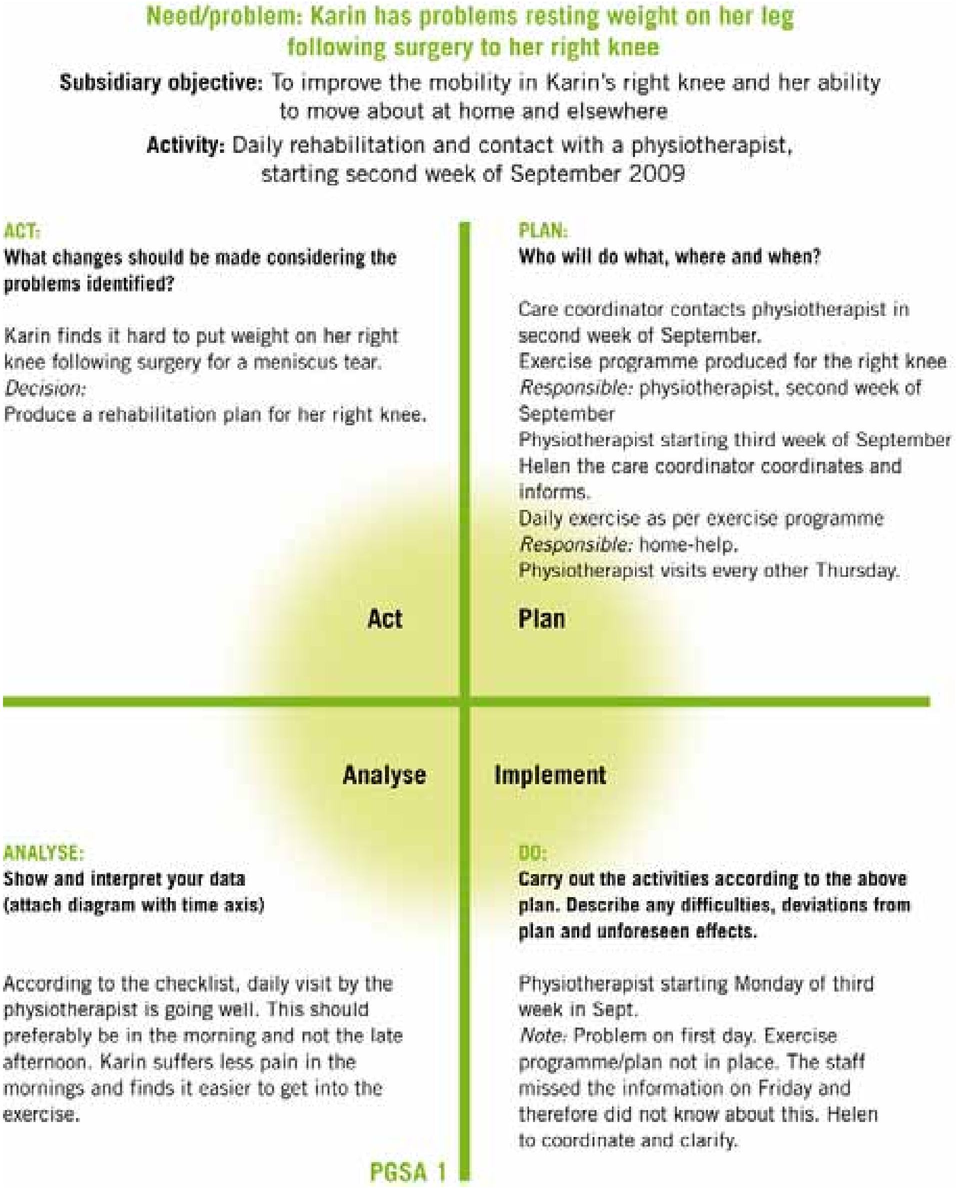
A common health and social care plan can be described as follows:

IMPROVEMENT MODEL – A SUMMARY

What do we want to achieve?	How do we know that changes really are improvements?	What specific activities can we do which will lead to improvements?
Describe improvement work/assignment (in brief): The team's assignment is to offer Karin Persson safe and secure treatment independently of healthcare personnel also covering preventative measures. **Overall objective:** For Karin Persson, aided by health/social care and rehabilitation, to manage daily life in her home and feel secure and satisfied	**Subsidiary objective:** Ability to move about in and out of doors **Measurements:** Compliance with rehabilitation plan	**Daily physiotherapy** **Contact with physiotherapist** PGSA 1
	Subsidiary objective: Being free of pain **Measurements:** Visual analogue scale – VAS	**Pain followed up daily with VAS** **Pain relief as required** PGSA 2
	Subsidiary objective: Preventing falls – Vision Zero **Measurements:** Fall och incident frekvens	**Review of indoor and outdoor environment** **Draw up checklists** PGSA 3
	Subsidiary objective: Having an appetite, feeling hungry **Measurements:** Dietary records, weight	**Serve desired dishes** **Company at mealtimes** PGSA 4
	Subsidiary objective: Ability to walk unaided **Mätningar:** Number of walks/week	**Walking exercise indoors and out 2-3 times per week** PGSA 5
	Subsidiary objective: Managing own hygiene **Measurements:** Record number of showers	**Daily support with self-help** PGSA 6
	Subsidiary objective: Feeling confident and secure **Measurements:** Perceived quality-of-life	**Conversation and social interaction** PGSA 7
	Subsidiary objective: Reducing the number of drugs **Measurements:** Compliance with prescribed medication	**Review of 13 different drugs** PGSA 8

Source: AMI

Every health and social care plan should be worked out in detail and continuously updated. See the following example:



Need/problem: Karin has problems resting weight on her leg following surgery to her right knee

Subsidiary objective: To improve the mobility in Karin's right knee and her ability to move about at home and elsewhere

Activity: Daily rehabilitation and contact with a physiotherapist, starting second week of September 2009

ACT:
What changes should be made considering the problems identified?

Karin finds it hard to put weight on her right knee following surgery for a meniscus tear.
Decision:
Produce a rehabilitation plan for her right knee.

PLAN:
Who will do what, where and when?

Care coordinator contacts physiotherapist in second week of September.
Exercise programme produced for the right knee
Responsible: physiotherapist, second week of September
Physiotherapist starting third week of September
Helen the care coordinator coordinates and informs.
Daily exercise as per exercise programme
Responsible: home-help.
Physiotherapist visits every other Thursday.

ANALYSE:
Show and interpret your data (attach diagram with time axis)

According to the checklist, daily visit by the physiotherapist is going well. This should preferably be in the morning and not the late afternoon. Karin suffers less pain in the mornings and finds it easier to get into the exercise.

DO:
Carry out the activities according to the above plan. Describe any difficulties, deviations from plan and unforeseen effects.

Physiotherapist starting Monday of third week in Sept.
Note: Problem on first day. Exercise programme/plan not in place. The staff missed the information on Friday and therefore did not know about this. Helen to coordinate and clarify.

The planning is supported by e-services with templates that continuously document the efforts made. Those authorised to view information can gain a quick overview of objectives, problems, measures and outcomes. The planning is structured and the efforts and measures may have a direct link to health and social care problems and objectives. Irrespective of health and social care provider, the patient's influence should always be a part of the new working methods and routines.

8.3 Prerequisites and bases– *a future scenario*

We will now define certain prerequisites or bases for our future scenario. These are also examples – naturally, local variations must always be borne in mind.

In a health and social care district, it has been decided to design health and social care for elderly people and patients with complex needs in a new way. The district wants to give this group better health and social care through a new *virtual organisation* and new ways of working.

The politicians in the municipality and primary care are agreed that new forms of collaboration must be introduced and have therefore decided to participate in a *patient project* in which a new *care concept* will be tried. Finances have been increasingly stretched in recent years and therefore it is not sufficient for the project to bring about mere value creation – preferably, it should lead to cost savings but under no circumstances must it lead to cost increases. For this reason, the financial consequences of the new healthcare concept are to be followed up and evaluated.

The new health and social care concept is characterised by:

- The patient/user and relatives being more involved in and able to influence the health and social care required – all to create more value for the patient.
- Health and social care planning leading to efforts to meet individual needs.
- A care coordinator leading the team created for each patient.
- An increasing amount of health and social care taking place in or near the individual home.
- More emphasis on preventative health and social care efforts.
- More self-care in the sense that the patient's own abilities are taken into account.
- Various professions collaborating across health and social care organisational boundaries.
- Implementation of an organisationally-independent and process-orientated workplace.
- Information technology becoming a facilitator and value-created for the patient/user.

- Introduction of mutual and more standardised funding of the operation.
- New types of reimbursement system, with reimbursement given according to health and social care results achieved.

Health and social care managers at relevant units have met on four occasions and consider they have a good idea and common understanding of what they and the politicians want to bring about.

The municipality has now conducted an inventory which shows that there are 230 people with complex needs for health and social care efforts. An individual assessment has been made in each separate case with criteria including age.

Many of the elderly people are in good health and have a functioning social network. These have merely been placed on a “watch list”.

The health centre has participated in the inventory and a number of younger patients with complex health and social care needs have thereby been detected and will be included in the effort.

The patient project will not be comprehensive in the sense that all users will be covered. Small-scale test comprising 25 users will be carried out instead. Following an evaluation, a decision will be made regarding possible extension.

A *leadership group* has been appointed, including representatives from various health and social care units and with medical specialists taking the decisions required to create the right conditions for the patient’s care.

The leadership group has selected five staff to take on a key role in the trial – that of care coordinator. This is a new role with new duties and powers. The concept is based on each patient/user having a care coordinator who, in conjunction with the patient/user (designated “the patient” in the scenario) and any relatives, will have responsibility for coordinating the necessary efforts to deal with problems and needs. The care coordinator will coordinate the design of health and social care objectives for the problems and needs identified. The efforts thus create the greatest possible value for the patient.

The ongoing health and social care planning now takes place in a structured fashion.

The care coordinator works purposefully to create knowledge and understanding of what the patient considers important in his/her care situation. This is in order to contribute in the best way to the right efforts being offered. Since the patient has comprehensive needs, a care team is required; this is drawn from different organisations with several different types of competences. The care coordinator is responsible for building up this care team and is authorised by the leadership group to distribute the necessary resources for each health/social care recipient.

The care team is needs-adapted and may vary somewhat over time but it is important to limit it to as few people as possible and ensure continuity of contact. The general practitioner is often a key person in this group, even if their time input may be somewhat limited. Continuity, approach and access are vital to creating security and stability. If this succeeds, the conditions are created for a more far-reaching delegation of various tasks than previously. For this reason, we would advocate a situation in which the attending physician has care of elderly people and those with multiple illnesses as a principal duty.

The care coordinator, along with others in the same role, also has responsibility for building up a local network of health and social care providers who can be called upon as required. Perhaps the most important resource in this external network is the hospital. Another important actor for many elderly people is Pharmacept, which can be employed as a consultant assisting in the complicated assessments linked to elderly people's use of medicines.

The care team will function so well that there will be much less need to contact A&E, but that when it is required there are well-prepared routines for how elderly people and those with multiple illnesses should be received and treated.

The days are gone when a visit to the clinic meant a six or eight hour wait to see a doctor with limited experience of the health issues of elderly people and those with multiple illnesses. Now, the patient will be rapidly dealt with on the department where ongoing care is to take place.

The care team can now also work preventatively as there is a common profile of and knowledge about the patient. Team members are well informed and many of the complications which previously affected the patient (such as incorrect use of medications) have been drastically reduced.

The local network includes not only healthcare personnel of various kinds but also other healthcare providers and meeting places which can contribute to wellbeing and good healthcare.

In summary, it might be said that we have created a *three-level* actor model:

- ***Patient level*** (the nucleus)
    - Patient – in this example, an elderly person with multiple illnesses
    - Relatives
    - Care coordinator – maybe a person from the municipality, county council or private care organisation, but must be able to influence municipal, county council-controlled and even private actors' efforts and have a mandate to build the team and order the services the patient requires.

- ***Intermediate level*** – The team level. The team is composed in order to deal with the major portion of the patient's needs (80-90%).
    - General practitioner
    - Health visitor
    - Social care (home-help)
    - Municipal district nurse
    - Occupational therapist
    - Physiotherapist

Health and social care providers at intermediate level should be stable and not subject to frequent change. The team is needs-adapted, i.e. new competences may need to be introduced, whilst others are perhaps no longer needed in the process.

- ***External level*** – the local network of external consultants/experts/specialists and various organisations and resources required to manage those medical problems which the *care team* cannot deal with alone, as well as contributing efforts of the more preventative or social nature.
    - Hospital A&E
    - Pharmacept
    - Specialists
    - Other special areas such as dental care
    - Voluntary organisations and interest groups

8.4 Change management and success factors

In order to succeed with transformation of the system from a situation like the current one to the desired vision requires comprehensive work to be carried out even as health and social care is given to those patients who need it. In our view, the work would be easier if it could be conducted in an environment of learning and exchange of experiences. There is now sound experience with the Breakthrough Method and Collaboratives [27] with the creation of forums for repeated planning activities and where teams from a number of districts can participate for mutual learning and to exchange experiences. These programmes are led by experienced change agents who can supply competence and have the ability to create effective learning situations.

Changing such all-embracing operations as elderly care in Sweden is a major challenge. In this project, we have found that changes are urgent and have high political priority. At the same time, there is frustration in many quarters over the sluggishness and many obstacles that make change take far too long. Much research is being conducted within the elderly field, but tends to be somewhat specialised and fragmented. A competence and learning centre which can help make change management more efficient, develop dissemination mechanisms for good solutions and spread experiences to and from all the local change projects that have started or will start, would satisfy pressing needs. Such a learning centre could also build up knowledge about and exploit the opportunities provided by Web2.0 including those of developing and generating information which can be reused.

There is knowledge from previous change management about what leads to successful projects. Important success factors are:

- Strong backup from the management, who also act as system designers – i.e. they create the required conditions.
- A well thought-out value basis including patient-centredness.
- Clear objectives, fact-based work.
- Good methods providing systematics and structure.
- Enthusiastic people.
- Competence.

The American researcher and paediatrician Paul Batalden and his colleagues searched out successful microsystems in health and social care [44]. They found that successful ones had the following features in common:

1. Their operation had a clear purpose.
2. They knew which patients they existed for.
3. They knew what needs these patients and their families had.
4. They had described and develop their processes.
5. They monitored and acted on the basis of their results.
6. They carried out team-based work with their staff.

There are *microsystems* [19] such as surgeries and clinical units – which achieve fantastically good healthcare based on science, comparisons and specific and unique knowledge about what “this patient” needs and wants. These units use consistent data to represent what they are achieving, monitor and arrange the work and improve their quality safety and efficiency. However, these units are still the exception!

Amongst the success factors, we find two of particular importance – leadership and value base – which warrant some further explanation of what we have found in the project.

Importance of leadership for collaboration and change

Leadership in the various operations which creates clear structures and provides the conditions to drive systematic improvement measures as well as creating consensus around value bases (Good Healthcare [20]). A leadership which has the courage to consistently work for the patients' best and break with existing structures when required. For this reason, it is important to introduce the work with a preliminary process in which the leadership jointly works through the problem, arrives at a common strategy and creates some form of contract in which they undertake to do their share of the work.

In this way, the conditions are also created for the care teams who must carry out the direct work to develop their routines and working methods.

Since finance is so much a controlling factor for all activity, it is important to be able to give early and clear demonstration that it is not merely about increasing resource efforts but also that the concept contributes to a lower overall cost. Not only do better collaboration and planning create more value for patients, they also lead to a reduced risk of needlessly duplicated work. This has been demonstrated in various studies [29].

There are good examples of change management showing that systemic and conceptual boundaries can advantageously be extended with the patient's needs at the centre, so as to encompass not merely one clinic or one hospital or one county council. For healthcare to be truly effective requires things like nursing, elderly care and pharmacies to work together to create the best solutions for the patient. Such a fully comprehensive outlook requires the collaboration of many actors.

The role of leadership is to clear obstacles from the path of various professions, authorities, actors and medical divisions working together. Leadership includes being a driving force and a system designer, in other words generating the necessary conditions to create value for the patients. For this reason, leadership on various levels is crucially important to whether medical care can cope with the challenges it faces and make the necessary changes. In the interviews we have conducted, quite strong criticism has been levelled at the lack of leadership so far shown.

The meaning of leadership for collaboration cannot be emphasised enough. In conjunction with initiatives to develop collaboration, leadership often finds itself in a conflict of loyalties between applicable regulations and reimbursement systems in the vertical organisational structures and the new network-based models of collaboration which are often required in order to deal with problems.

The task of leadership is to create the circumstances for local teams to develop their forms of collaboration. According to Marie Fridolf [25], there is a logical order which begins by looking at one's limitations. When one can see the incongruities in these limitations, new steps can be taken.

The second stage proceeds from value creation for the patient. What collaboration is required in order to create value? The horizontal work can start. Meeting places and arenas for this work are created.

In this work, problems and deficiencies are identified in health and social care. The starting point is always value for the patient and thereby an integrated view of the problem.

Learning is created in which in which the individual operation is set in a broader context. Based on this learning, areas for improvement are identified and methods developed.

Often, this leads to a realisation that new working methods cannot be rewarded and in fact must even perhaps be punished by the old vertical measurement systems. New measurement systems need to be developed. Achieving this requires the advent of new common goals, decisions, resources and structures.

As indicated in an earlier section, a possible strategy might be to create a consensus at leadership level with representation of the various operations affected. This work can commence with an agreement on a common value bases and identification of deficiencies and problems directly affecting opportunities to create value for the patient. Common objectives (visions) could then be drawn up as to what should be done and discussion held on how collaboration can be designed and how to achieve it. Naturally, this work at leadership level needs to be made permanent, as new issues will always rise and need attention at leadership level.

Through VVP, a preliminary process has thus been implemented in both Jönköping and Angered. In both cases, there are good opportunities to improve healthcare and create added value, but it is dependent in each case on how the leadership level approaches the task and how they use the will for change amongst the contributors.

Value base and value creation

Value bases are those values which control the behaviour and actions of health and social care personnel. The Swedish Board of Health and Welfare’s publication entitled Good Healthcare [20] gives an indication as what may be regarded as suitable value base for healthcare.

The value base should not be confused with value creation, which aims to generate value for a patient. Value creation is highly individual even if it is naturally the case that there are many elderly people with the same concept of what kind of value they want their care providers to supply or offer. Something similar applies to people with neuropsychiatric disorders and other groups with complex care needs.

Our interpretation is that health and social care personnel in operation should have a common view of how to relate to patients and elderly people, how to approach them, what to prioritise etc. in order to provide good healthcare and be able to create value for those for whom the healthcare is intended.

For this reason, improvement measures must always be based upon an accepted and applied value base. A good example of how a common value base can be formulated exists in Gotland where Good Healthcare [20] has been used as a basis and then a policy document designed which can be used for local improvement measures.

Proceeding from a common value base also facilitates improvement measures aimed at improving the health and social care processes. This is particularly so when it concerns bringing about an interorganisational process where functional and professional structures will want to conserve and safeguard their special interests. Thus, basing one’s efforts and initiatives on an aim to create added value for the patient can never be questioned.

9 Further research

Proposed further research

As well as the results reported, in the VVP project we have also observed that further research is required. A number of possible projects have been outlined.

In brief, we would emphasise that the proposals we have presented need to be tested in concrete change management projects. These should comprise a part of the transformation being sought. Projects are designed so that assessment and learning are a natural part of the process. There is valuable experience to be gained in the project design from the Triple Helix in which Public Sector, Research and Industry collaborate from models tested in "Living Labs" and from the Breakthrough Method [27] etc. It would be advantageous if more regions could participate so that forums for learning can be established.

The following may be mentioned from among the proposals for further research in the final report:

1 *Further studies of collaboration-supporting and patient-focused e-services*
First and foremost, the new types of collaboration-supporting e-services proposed need to be further developed and tested in a real care environment with evaluation of how they can facilitate collaboration and information flow between healthcare inpatient and between the various actors in healthcare.

2 *Development and evaluation of a collaboration-orientated and cohesive new healthcare concept*. For example, the healthcare concept could be developed for elderly people and those with multiple illnesses focusing on individual needs and creating greater value for the patients than the care that is currently supplied.

3 *Clustered e-services and marketing/commercialisation*
To be attractive on the market, the new e-services probably need to be "clustered" into different logistical groups of individual companies, or consortia of companies. The possibility of creating such clusters should also be studied.

4 *Links to national IT strategies for health and social care*
How can the results currently produced in the national projects under the national IT strategy be linked to the results which have been created in the VVP project to create applicable results?

5 Probably, all new e-services to be introduced in Sweden should be allied and related to the more important national projects. At the same time, resources from such things as NI projects should be concretised and tested in real environments.

6 *Studies relating to integration with existing IT systems*
Studies need to be carried out relating to how to develop migration strategies in which modern, process-orientated e-services can be linked to existing case record systems or the like and where existing systems also play a role in renewal work.

7 *Research into economic impacts of new healthcare concepts*
Finally, we propose that research projects should be created in which studies of economic impacts of various new healthcare concepts and the like can be carried out. There is often discussion and argument around new healthcare models or concepts having one or the other size of economic impact. However there is a lack of empirical evidence for many of these arguments.

8 *Models for innovative public procurement*
As shown, the VVP project has found that an obstacle to the spread of innovative healthcare models and e-services is slowness on the part of the organisations. The same applies to the procurement rules within the public sector which prevent or at least complicate the introduction of new concepts. We therefore propose that studies be conducted to see how these obstacles can be removed.

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VINNOVA´s mission is to promote sustainable growth
by funding needs-driven research
and developing effective innovation systems

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