



NATIONAL STRATEGY FOR eHEALTH SWEDEN

Ministry of Health and Social Affairs
Swedish Association of Local Authorities and Regions
National Board of Health and Welfare
Medical Products Agency
National Corporation of Swedish Pharmacies
Carelink



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Executive summary

Information and communication technologies (ICT) offer numerous potential benefits in terms of improvements for patients, health and elderly care professionals and decision-makers. Citizens, patients and relatives must have quick, trouble-free access to quality-assured information on health care provision and health concerns, as well as personal data on their own care, treatment and health status. They must also be able to contact care services via the internet for assistance, advice or help with self-treatment. Health and elderly care professionals must have access to efficient, interoperable e-Health solutions that make it easier for them to perform their day-to-day work while guaranteeing patient safety. Authorities and other bodies responsible for care provision need ICT for effective follow-up of patient safety and quality concerns, and to support management functions and resource distribution.

A range of issues relating to ICT use must be solved at national level, based on the collaboration of all actors in the health care sector. These concerns must be dealt with on the basis of a common approach and nationally established guidelines and solutions. A national e-Health strategy is needed to ensure efficient and effective use of ICT. Used as a strategic tool, ICT will promote safer, more accessible and efficient health and elderly care services.

Most of the work of enhancing the efficiency and effectiveness of ICT use will naturally devolve on the county councils, municipal councils and private care providers concerned. In addition, a range of measures will be required from government at various levels and from other actors in the health and elderly care sector.

Increased use of e-Health must be combined with effective security measures designed to ensure that highly sensitive confidential information relating to individual

patients or users is securely handled by all involved in care or service delivery.

The work to be jointly undertaken is grouped into six action areas. The first three are concerned with establishing better basic conditions for ICT in health and elderly care. The last three are about improving e-Health solutions and adapting these to patient needs. Education, training and research initiatives are crucial to all six areas. They are:

1. Bringing laws and regulations into line with extended use of ICT.
2. Creating a common information structure.
3. Creating a common technical infrastructure.
4. Facilitating interoperable, supportive ICT systems.
5. Facilitating access to information across organisational boundaries.
6. Making information and services easily accessible to citizens.

The development of a national e-Health strategy constitutes the first stage of a long-term undertaking aimed at achieving a higher degree of collaboration at national level on these issues. The second phase, to be launched in 2006, will involve gaining support for the strategy among the country's county councils, municipal councils and other actors and stakeholders in the sector. Issues such as scope, scheduling, financing and decision-making procedures in connection with the work ahead will also be discussed at this stage. A policy position on the planning, implementation and financing of future work on ICT issues at national level will be taken by the National High-Level Group for e-Health on the basis of the outcome of these discussions. A report on how to proceed in the focal areas in the second phase is to be presented by March 2007. ■



A common e-Health strategy offers numerous potential benefits in terms of improvements and greater efficiency for patients, health care professionals, and decision-makers.

Vision statement

Appropriate ICT-based tools will help ensure that all patients receive adequate, safe, secure health care and good-quality service. Care professionals will be able to devote more time to patients and adapt care provision to individual needs. ICT will be used as a strategic tool at all levels in the care sector, and health care resources as a whole will be utilised more efficiently and effectively.

- Citizens, patients and relatives will enjoy quick, trouble-free access to all-round information on health care, health issues and their personal health status. They will receive good-quality service and be actively involved in their care and treatment according to their abilities and circumstances.
- Health and elderly care professionals will have access to efficient, interoperable e-Health solutions that guarantee patient safety and make it easier for them to carry out their day-to-day tasks.
- Authorities and other bodies responsible for care provision will have appropriate ICT-based tools for following up patient safety and quality concerns, and to support management functions and resource distribution.

Future scenario

The need for information about health and health care varies, as does the need to contact care services. Parents with young children need quick, trouble-free access to primary care services, advice on the treatment of minor complaints and simple procedures for medical consultations and routine tests. People suffering from chronic conditions need simple, safe

methods for monitoring and checking the progress of their own illnesses, regular contact with their specialists and access to information about new treatment methods. Elderly people may need assistance and medical attention in their own homes. Providing them with the security, quality and continuity they need often requires coordinated support from a number of health and elderly care providers. The health care services of the future will be based to a far greater extent than today on the needs, wishes and circumstances of the individual. People will receive information and guidance on an individual basis, and patients will have the opportunity to become more actively involved in their care and treatment and take more decisions of their own.

In the future, more and more people will seek individual, tailored solutions to their problems, take initiatives and make their own choices. Citizens will make the same demands of the health care sector as they do of other service providers in the community. The market for health-promoting, care-oriented activities, services and products will grow and the latter will be designed to meet user needs and wishes.

Citizens of the future will use the internet on an ever-increasing scale to learn more about health concerns, illnesses, symptoms, medicines and self-treatment. A nationally coordinated health portal will direct users to quality-assured information and up-to-date research findings at international, national and local level. The portal will also provide access to all available information on health care services, care quality and health products. Citizens will be able to choose among a range of alternatives. Personal advice and counselling will also be available.

Those who wish to book or change appointments with health care professionals, renew prescriptions or discuss a specific problem with their doctor will have access to

easy-to-use services through the web portal or on the telephone. Access to care or stored electronic health records (EHR) will no longer be hampered by administrative or geographical boundaries. EHRs will follow the citizen no matter where, when or from whom she or he has previously received care or medical attention, and regardless of whether contact is made from a summer cottage, the workplace or during a holiday abroad.

The portal will also link citizens to personal sites, where they can have secure access to their own health records and get an overview of relevant medicines and previous contacts made. They will also be able to enter notes or comments addressed to authorised health care professionals, and track other personnel who have had access to their records. Decisions as to who may read a person's records or any part of them will rest with the patient her-/himself.

Health care professionals will be able to access the ICT systems they need with a single sign-on to the usual system environment. Secure identification and authentication systems will enable doctors to access a patient's EHR and medical history, ongoing treatment and courses of medication – after securing the latter's consent – no matter where this information is stored. Treatment and examinations carried out at other treatment units can be booked easily via an electronic referral and booking system. Consultations with specialists, medical analyses, care planning and consensus assessments, including the procural of second opinions from other doctors, will be largely conducted using videoconferencing technology and secure email. Care professionals will make use of a range of ICT-based decision support systems when researching and planning courses of treatment. To ensure that care is based on documented studies and research, health care professionals will have access to clinical guidelines, the best approved care methods and multi-professional networks whenever decisions need to be made. The result will be better quality, shorter waiting times and more efficient resource utilisation. User-friendly ICT systems will cut down time-consuming administration for all personnel so that more valuable time can be spent on vital meetings between the doctor and patient.

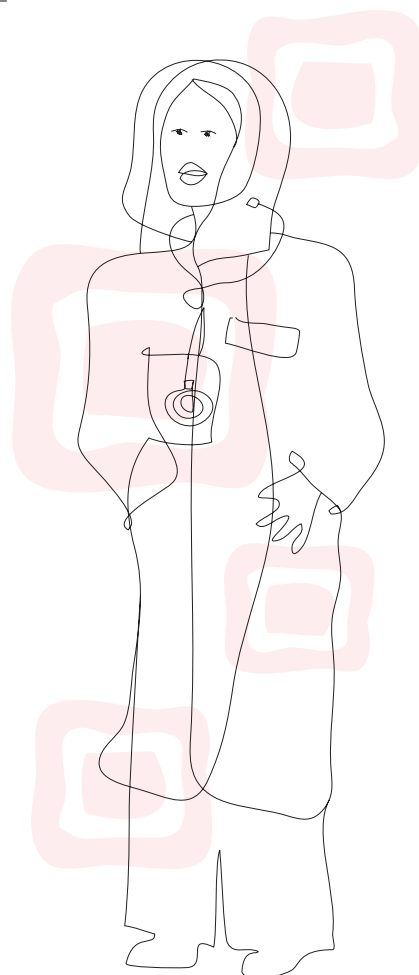
When an elderly person is discharged from hospital, outpatient or primary care personnel will have access to the information they need to prepare and plan continued treatment and other interventions. Nurses in the elderly care services will have electronic access to up-to-date discharge letters, and to the care receiver's in-patient health records for information about her/his treatment history and newly and previously prescribed medicines.

EHRs can be accessed in anonymous form, e.g. for statistical purposes, and used as a long-term, common

resource. Interoperable ICT-based tools – in the form of quality and health data registers – will allow relevant authorities to follow up and assess the quality and efficiency of care services, and track changes in diseases, care consumption and drug use. We will also be better able to detect and prevent epidemics and other global health threats. The information will serve to improve patient safety by helping us to continuously develop our knowledge, create efficient, standardised care programmes and follow up activities at local level.

Although new information technology is an efficient tool, both for the citizen and health care professionals, it must always be used in accordance with the wishes of the individual. ICT is an obvious tool for many people, but not for all. To ensure no one is excluded, there must always be alternative ways of accessing information and contacting and communicating with care services. Different people need different forms of support and guidance.

This vision of tomorrow's health and elderly care services and their functioning can only be realised if ICT use is placed in a new operational perspective focused on the common need for secure, efficient and accessible care. ■



Better health and elderly care services for the individual and the community

The Swedish health care system

Sweden has a decentralised health care system, with 20 county councils and 290 municipal councils as principals and care providers. Their responsibility as principals includes the provision of adequate care services and the requirement to develop, quality-assure and finance all care activities. Both county and municipal councils employ the services of private care providers to a greater or lesser extent.

Under the terms of the Health and Medical Services Act, county councils are required to provide health and medical care of a high standard to all those resident in the county. Health and medical care planning must be based on the inhabitants' care needs and include health and medical care services offered by private and other care providers.

The act also requires municipal councils to offer health and medical care of a high standard to specific groups, including the elderly and the disabled. Since the 1992 Ädel reform, which made the municipalities responsible for long-term services and care for the elderly, many older people are able to remain in their homes with support from the health and medical care and social services.

The future allocation of competences between the state, county councils and municipal councils is currently the subject of an inquiry by the Committee on Public Sector Responsibilities (*Ansvarskommittén – Dir 2003:10¹*). The

committee's findings, to be published in February 2007, will affect the way the health and social care sector will be organised and financed in the future.

Health care goals

Section 2 of the Health and Medical Services Act states that the overall goal of the health and medical care services is a healthy population and health care on equal terms. Priority is to be given to those in greatest need of care.

There is broad agreement on a number of criteria that must be met if health and elderly care is to be considered of a "high standard". Health and elderly care services must:

- be of good quality, based on scientifically established knowledge and proven experience
- be based on respect for patients' dignity and right to self-determination, and be open to patient participation and influence
- be accessible
- offer patients the greatest possible degree of choice
- provide citizens and patients with comprehensive information on access to health and elderly care and on the quality and effect of these services
- use care resources efficiently, effectively and responsibly.

Efficient and effective health and elderly care is not only vital to the health, security and wellbeing of individual citizens, but also to people's confidence in society's ability to meet their basic needs.

1. Terms of reference.

Health care in transition

Growing demands and expectations

The Swedish health care system, like those of all other countries, faces major challenges. It must:

- deliver health and elderly care to an ageing population
- meet rapidly growing demands for appropriate, individually tailored care using existing resources
- adapt care structures and content to patients' and citizens' needs. Stepping up the provision of health care and social services in the home is one example
- enable patients and their families to play an active role in decisions relating to health care provision and delivery
- offer internationally competitive, high-quality health and elderly care
- meet the need for cross-border care and facilitate greater mobility among patients and care professionals in cooperation with other EU countries.

Development and change in the care sector

To meet the challenges facing the health care services, intensive, wide-ranging efforts are being made to develop and improve the efficiency of the whole system at all levels, from changes in individual patient care to a restructuring of the entire organisation.

These include:

- ensuring more rapid dissemination of new knowledge, e.g. through the continual introduction of new, more effective diagnostic and treatment methods
- ensuring better care for patients who require treatment from different care providers
- ensuring more efficient utilisation of advanced equipment and qualified personnel
- implementing organisational changes relating to care delivery. Continuing the transition to out-patient medical care and stepping up care provision in the home are two examples
- ensuring that care professionals have access to continuing professional development
- providing citizens and patients with information on all important aspects of health care, such as access, quality, treatment results, service, rights and alternative treatment forms.

From an organisational perspective to a patient perspective

A feature of ongoing development work is the gradual transformation of the system's relationship to patients. In the past, the emphasis has been on improving and enhancing the efficiency of care services on the basis of assessments by care professionals of how an efficient operation should be run, and on an organisation-based view of efficiency and appropriateness. The new approach, gradually adopted over the last few decades,

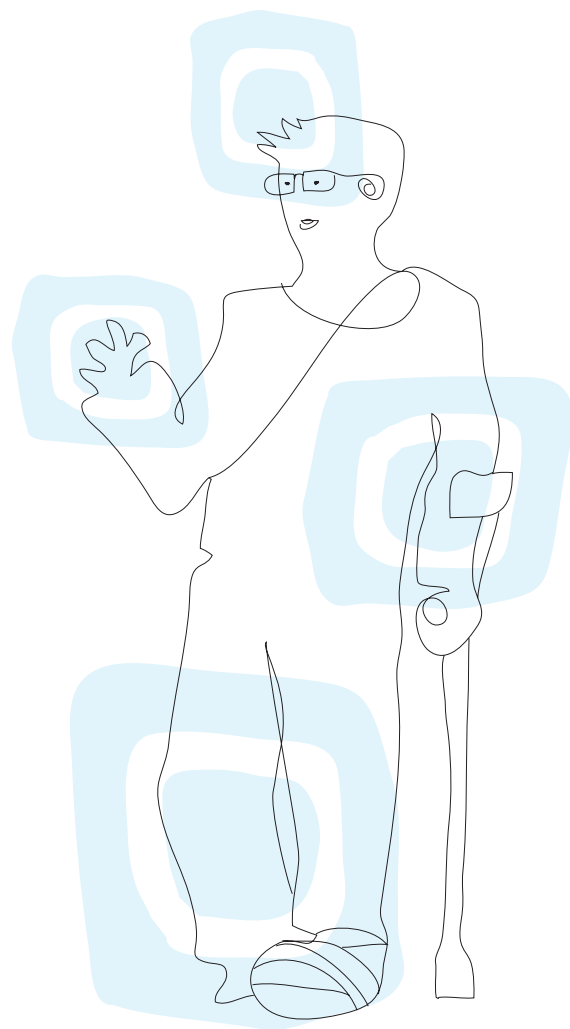
is based on citizens' and patients' actual needs and emphasises the value of active patient participation. Development and reform measures must first of all be assessed on the basis of whether and how they help improve conditions for those affected by them.

ICT – a versatile tool offering new possibilities

ICT increasingly important

Today, ICT is employed everywhere in the health care system, for different purposes and in different ways. However, it is deployed less extensively than in many other sectors of society, and far less than it could – and should – be.

Mounting calls for more effective e-Health solutions coincide with the growing need for more and better ICT support in light of the impending organisational and operational changes to the system.



ICT use insufficiently coordinated

ICT has never been used to its full potential. Until now its use has been confined to delimited areas of the health care system. There are several reasons for this: difficulty in agreeing on the specific requirements for interoperable e-Health solutions, the fact that the need for communication was not as great in the past, and the high cost of advanced ICT systems. Many of the ICT-based tools deployed in hospitals, primary care and municipally-run care services are only used for a small fraction of the tasks they are capable of sustaining, and interoperability is limited.

Moreover, major investment in different e-Health solutions has not been accompanied by a corresponding commitment to developing user skills, with the result that care professionals have not always been able to reap the intended benefits. Investment in ICT support for net-based skills development and training (e-Learning) also lags behind investment in other forms of ICT support in the health care sector. It should be possible to make greater use of the ICT infrastructure developed for the care services as a platform for e-Learning. Health and elderly care provision are knowledge-based, skills-intensive sectors, and knowledge and skills must be continually renewed.

e-Health solutions fail to have intended effects

Although e-Health solutions have had a number of beneficial effects, they have seldom wholly fulfilled expectations. Moreover, installation and maintenance costs have frequently outrun original estimates. There are a number of reasons for this, which are not unique to the care services. One is the tendency to underestimate the difficulties and cost of introducing e-Health solutions in ways that will bring about desired improvements. Another is that the various tools already in place are seriously underused.

The limitations and shortcomings of present-day ICT-based tools can be summarised as follows:

- County councils and municipal councils use ICT differently, and the infrastructure for the many services provided is unevenly developed. As a result, e-Health solutions in different care units often:
 - have trouble exchanging information
 - cannot easily accommodate new functions and features, such as decision support in different treatment situations
 - cannot easily compile and communicate information to accounting and management systems at executive and principal level, or to national registers such as health data and quality registers
 - lack established common user interfaces which makes it difficult for care professionals to use them
 - are not technically designed for cost-effective operation and management.

- Patients cannot themselves easily access and read their health records or information compiled about them by care professionals. Electronic access to service and help with minor health problems is also limited.

ICT in a new strategic operational perspective

A new approach is needed

A great deal needs to be done to improve ICT use in health care. For example, there is a need for better decision-making bases and decision-making processes whenever new e-Health solutions are introduced or changed. Operation and management of ICT support can also be improved. Although such improvements are urgent, they will not suffice to develop and improve Swedish health care. Rather, what is needed is a new basic approach to e-Health solutions – a strategic operational perspective.

Modern ICT creates new opportunities

Modern ICT makes it technically possible to organise, coordinate and deliver health care and carry out clinical research in ways that were previously unthinkable – or at any rate wholly impracticable – at a reasonable cost. Citizens and health care providers alike benefit in numerous ways from this new potential.

Citizens and patients will increasingly be able to play an active role in and bring their influence to bear on health care provision chiefly because of the wider range of choice available to them. They have a number of legitimate demands with regard to health care, which in turn require access to information. These demands can be met to a significantly greater extent with the help of ICT. The following are fundamental and self-evident:

- Simple procedures for finding and contacting care units of different types and for following up their own care, for example to ascertain their referral status.
- Access to information relating to care needs, symptoms, illnesses and treatment.
- Information on available health care options, their quality and results.
- Choice in health care; information about the care guarantee and its significance.
- Trouble-free access to electronically stored information such as diagnoses, test results, measures taken and medicines prescribed.
- Access to information on patients' rights in relation to care and treatment.

Care providers and professionals at all levels stand to benefit in the following ways:

- Information registered in one place in the health care system can be made available at other points, as needed, at any time of the day and without technical difficulty.
- Communication between patients and care services can in many cases take place electronically, via web interfaces and secure email.
- Care providers, care units, patients and their families will be able to communicate with one another in new ways, e.g. videoconferencing and other transmission media. This is already happening in a number of places, for example when elderly patients are discharged from hospital to receive continued care in their homes.
- Medical expertise can be obtained at a distance.
- ICT-based tools for documentation and administrative purposes in clinical care can be supplemented by other knowledge and decision support systems.
- Registered information relating to care and treatment can be utilised in various ways: for management, and follow-up purposes, in research, development and quality assurance. This is often done using special registers and databases.
- Internet-based e-learning provides an ideal environment for organising and implementing continuing professional development and further training in more flexible formats tailored to individual needs.

Efficient, interoperable e-Health solutions can help reduce the number of hours spent on administrative tasks and enable health care professionals to devote more time to meeting patients. They can also help reduce the incidence of wrong or inappropriate treatment. Incorrectly prescribed medicines are one example. ICT-based tools can also promote greater patient participation and improve care accessibility.

The new opportunities: content and end results

Each new potential improvement means little in itself. Many have been in existence for a long time, often subject to technical or cost limitations. Together, however, they create a wholly new situation, one which should lead to a sweeping review of the health care organisation, its working methods and its relationship with its patients.

If ICT use continues to be handled in the same restricted way as in the past, support will remain fragmented and poorly coordinated. Although improvements of this kind will undoubtedly benefit the activities they are intended to support, they will have none of the beneficial effects they would otherwise confer on the individual citizen, the community or the health care services as a whole. To achieve the latter, a different approach to

future ICT use will be necessary. Principals and their management groups must reach a decision on how they want the health care system to work in the future and what its relationship to patients should be. Ultimately, it is a matter of viewing ICT expansion from a strategic operational perspective on the aimed-for development of the health care system.

In the long term, this approach could also result in an R&D-friendly environment, where conditions are increasingly conducive to the development of advanced ICT-based tools and medical devices for health and elderly care, thereby generating favourable export opportunities for companies active in Sweden.

A strategic operational perspective on ICT use does not mean we must immediately take up a position on every issue. Initially important tasks include:

- enhancing the status of citizens and patients and providing greater scope for participation
- delivering health care unimpeded by operational or administrative boundaries or geographical distance
- providing care professionals with user-friendly, quality- and skills enhancing work tools
- seeking to ensure good resource management and economic efficiency in the health care services
- creating conditions conducive to ICT use in health care.

Keynotes for a strategic operational perspective on ICT

As mentioned in the previous section, the principal actors in this sector must take up a common position on five strategic issues crucial to the continued development, renewal and improved efficiency of Sweden's health care services. Their standpoints on these issues will have direct repercussions for future ICT use in care provision.

1. Enhancing the status of citizens and patients and providing greater scope for participation

The status and active participation of citizens and patients has been strengthened, a development reflected in public values and recent legislation. Patients and their families now have better access to information on health care. The greater ease, in practical terms, in contacting and bringing influence to bear on health care services has encouraged participation. Efforts to increase this type of participation will continue and will directly affect the design of e-Health solutions and access by patients and their families to different types of information.

2. Delivering health care unimpeded by operational or administrative boundaries or geographical distance

A range of factors make it increasingly important that health care services function unimpeded by operational or administrative boundaries or geographical distance. Health care needs are greatest at local level, with resources mainly concentrated on the elderly and mentally ill. Responsibility for care provision in these areas is shared by the county councils and municipalities, an arrangement which requires close collaboration.

Mobility in the population is growing as a result of moves by students in higher education, changes in employment and residence and moves from winter to summer homes. Health services must be capable of functioning without interruption even when people move or live in more than one place. Another reason for ensuring that health care services can operate across boundaries of different kinds is that many types of care need to be concentrated in a limited number of care units, in extreme cases within a single national facility. Moreover, the long-held right of patients to opt for care or treatment in another district or locality – as well as the possibility to do so – has been further strengthened since the introduction in 2003 of free choice in health care. The newly introduced health care guarantee is likely to further increase patient mobility.

3. Providing care professionals with user-friendly, quality- and skills-enhancing work tools

As ICT use in the Swedish health care services is uneven and relatively low in overall terms, there is a need for greater, more evenly distributed access to effective e-Health solutions.

Existing ICT-based tools must not only be user-friendly but also simplify routine health care procedures. Tools should preferably have a common user interface and shared sign-on, security and communication functions. There is room for improvement and a need for closer inter-service cooperation in this area.

Accessibility and service can be improved substantially with the help of ICT. In addition, the skills and expertise of care professional can be considerably enhanced by knowledge-based specialised decision support systems. Among other things, this can help reduce the risk of inadequate or inappropriate treatment, such as wrongly prescribed medicines. This process has only just begun and cooperation at national level will be needed if the best expertise is to be secured.

4. Seeking to ensure good resource management and economic efficiency in the health care services

ICT has long been used in the planning, management and follow up of health care services. Continual devel-

opment and improvement of e-Health solutions in these areas is clearly vital. Cutting waiting times, coordinating patient care and reducing the administrative workload of care professionals with the help of ICT are also pressing concerns.

ICT also offers a number of possibilities for improving resource management from a strategic standpoint. One is to procure skilled diagnostic services electronically, e.g. in the fields of radiology and laboratory medicine. Another is more efficient use of qualified personnel through the creation of professional networks. For instance, it is already technically possible to coordinate on-call periods for health care professionals in a number of specialist areas in a county council, across a health care region and at national level.

The scope for ensuring more efficient and effective use of skilled personnel and often scarce resources is growing rapidly. In many cases, this potential is predicated on close cooperation between several principals or co-operation at national and international level.

5. Creating conditions for ICT use in health care

The use and expansion of ICT in health care is hampered by a number of general problems and factors affecting the ability to apply the technology effectively. By and large, these problems and deficiencies can be grouped into three main areas: the need for changes in legislation, the requirement that information (nomenclature and concepts) be uniformly defined, and the need to improve the ICT infrastructure.

To create conditions generally conducive to ICT use in the health care services, we therefore need to:

- bring legislation and other regulations into line with increased ICT use while maintaining full protection of personal privacy
- create a national information structure for the health care services
- further develop the national technical health care infrastructure with a view to creating a secure electronic communication system capable of linking care units and supporting advanced medical devices.

Intra-sectoral cooperation essential

In the Swedish health care system, responsibility for investment in new e-Health solutions rests with the principals, i.e. the county and municipal councils and the private care providers they engage. A strategic operational perspective on ICT use in health care therefore presupposes broad collaboration among all actors

and stakeholders in the sector. It is essential that principals and the government adopt a common approach to strategic ICT issues. Other actors involved in health care provision and delivery must also contribute to the development and use of efficient, interoperable ICT-based tools.

The five key points in the strategic operational perspective on ICT use in care must not infringe on the basic decentralised structure of the Swedish health care system. If the system is to be developed and improved, however, cooperation on a range of ICT-related issues is essential if care resources are to be utilised more efficiently and responsibly, while retaining the existing division of responsibility between county councils and municipalities.

Management, coordination and cooperation at national level

Overall national management and coordination

Tomorrow's e-Health solutions must be coordinated at national level and be underpinned by a common technical infrastructure. ICT use must therefore be managed, coordinated and followed up at national level. Responsibility for this task currently rests with the body that drew up the National e-Health Strategy, the National High-Level Group for e-Health.

Cooperation at national level

The National e-Health Strategy requires that all actors in the care sector cooperate on a number of issues at national level. The main objectives here are to create the basic preconditions for ICT use, including the harmonisation of legislation and other regulations and the establishment of an information structure and a technical infrastructure, and to develop application-oriented e-Health solutions for common tasks and functions in the health care sector.

There are additional reasons for cooperation at national level, the most important of which is the need to keep costs under control. Others concern personnel policy, such as the need for adequate ICT training at all training levels in the care services. Major training initiatives should be undertaken on a joint basis to facilitate collaboration between different professional groups and other areas of the health care services. Also needed is a broad selection of suitable further training programmes and courses for different professional groups and decision-makers.

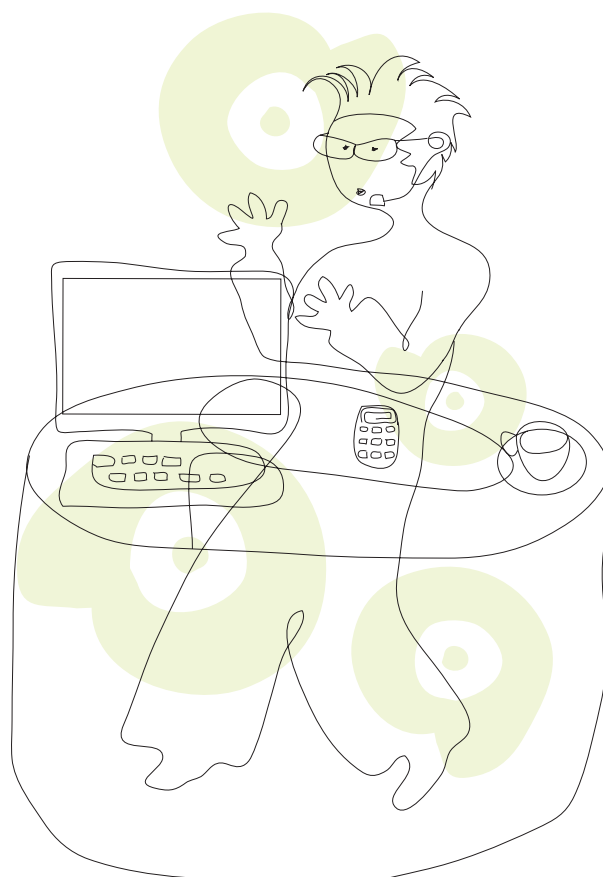
Cooperation at national level is justified on a number of grounds. Although the same conditions often obtain,

there may be differences with regard to details, scope and timescales. This makes it more difficult to estimate and allocate costs arising exclusively in connection with e-Health strategy work at national level.

Cooperation must be structured, made concrete and incorporated into an action programme. The work must also be financed and planning and implementation tasks allocated to duly designated bodies.

Health care from an EU perspective

People are becoming increasingly mobile. Growing numbers work wholly or partly in countries of which they are not citizens. Young people often go abroad to study, many visit other countries as tourists, and retired people live abroad for extended periods. If an EU member state is unable to meet urgent health care needs within a reasonable time, EU citizens now have the right to seek treatment in another EU country. This means health care services must work unhindered by national boundaries, which in turn presupposes the gradual harmonisation of health care systems in Sweden and other member states. One of the most im-



portant concerns of EU cooperation in the health and medical care sphere is to ensure patient safety when a citizen seeks treatment in another member state. Efforts must therefore be made to ensure that relevant information can be made available electronically in emergency cases as well as planned health care interventions.

Differences in ICT deployment and use by county councils and municipalities respectively hinder the effective exchange of information with health care units in other member states. These disparities will be a key argument for the national coordination of ICT use in Swedish health care.

stallation, operation and management of e-Health solutions under control.

One might reasonably ask how the National e-Health Strategy will affect the principals' local ICT strategies. The national strategy deals with those aspects of ICT use that an individual principal cannot or should not decide on independently, i.e. aspects that must be addressed and settled at national level if ICT use is to function efficiently and effectively from a strategic operational perspective on health care. Principals will accordingly be expected to incorporate the National e-Health Strategy into their own strategies. The aim of the national strategy is thus to facilitate the principals' tasks. ■

Strategy implications for the principals

The import of the National e-Health Strategy in brief

The National e-Health Strategy entails a number of commitments on the part of the principals involved, namely the county councils, municipalities and private sector care providers. These will be expected to:

- take up a common position on the five operational issues of strategic importance to the development, efficiency enhancement and renewal of health care.
- acknowledge the need to address and solve a number of key issues concerning ICT use in health care on a joint basis at national level. County and municipal councils must also be prepared to help finance work undertaken at national level. The scope and financing of strategy implementation and associated decision-making procedures will be the subject of continued discussion and deliberation during 2006.

National e-Health strategy implications for the principals' operational and ICT strategies

Strong pressure to develop and improve the efficiency and effectiveness of health care services and tailor them to patient needs will compel all principals to implement changes in a range of areas. Thus, it will be to their advantage to formulate a local operational strategy that will guide the process and direction of change and place the required measures in a wider perspective.

ICT is an important part of many of the operational changes that will have to be made, and all principals will need a strategy for ICT use. This is essential if the various ICT-based tools are to be tailored to patient needs and interact effectively with one another. ICT strategies will also be needed to keep costs for the in-

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Action areas for cooperation and coordination at national level

Structures for action at national level

Increased use of ICT in the various operational areas of the health care system calls for more than mere descriptions of ICT use in the areas concerned.

Other measures are also required. This applies particularly to health care and care of the elderly, where private and highly sensitive information relating to individual citizens is handled in a decentralised structure in which responsibility is divided among numerous principals.

If ICT use is to deliver the intended benefits, extensive investment will need to be made in training and continuing professional development in health and medical care informatics and medical technology, i.e. information technology applications in health care. This applies to basic training of tomorrow's health care professionals as well as existing health and elderly care personnel and management staff. Training is also needed for those whose work involves product requirement specification, procurement of equipment and services and the development and installation of ICT systems.

Health care uses up a substantial proportion of society's resources and ICT is an increasingly important tool for a wide range of health care applications. Independent, unbiased research and other in-depth studies relating to ICT use in care, including its various requirements and effects, are therefore essential.

Increased ICT use cannot be achieved without basic improvements, including a uniform information structure, extended technical infrastructure and legislative

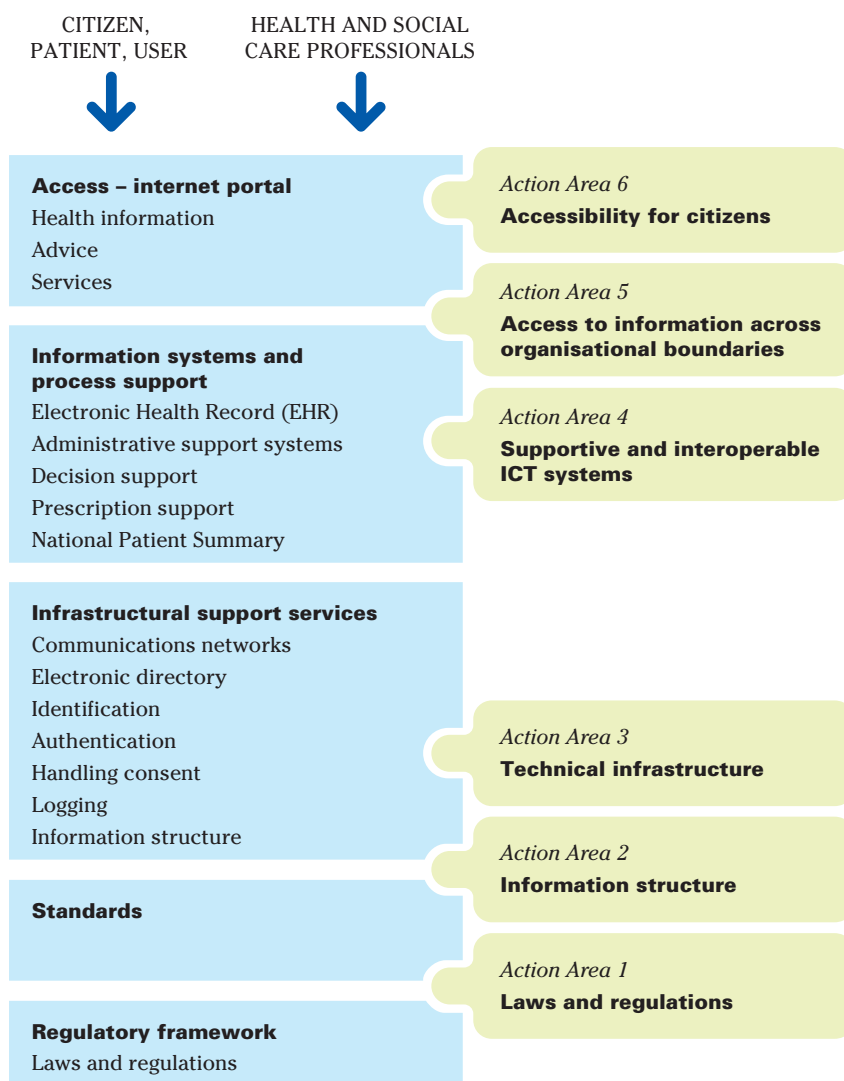
change. Action in these areas will yield substantial benefits for e-Health solutions of all types. ICT-based tools used in health care work and for communication between patients and care services also need improving. The necessary improvements have been grouped into six action areas with accompanying descriptions of what must be achieved in order to realise the ICT strategy's aims. It is essential that all county and municipal councils, private care providers and other actors and stakeholders contribute to this national collaborative undertaking in all action areas. Education, training and research initiatives are crucial in all six areas.

THE SIX ACTION AREAS ARE:

1. Bringing laws and regulations into line with extended use of ICT.
2. Creating a common information structure.
3. Creating a common technical infrastructure.
4. Facilitating interoperable, supportive ICT systems.
5. Facilitating access to information across organisational boundaries.
6. Making information and services easily accessible to citizens.

At present, there is no universally recognised description of the various health care processes and information flows that might serve as a basis for coordinated development and use of e-Health solutions. The level of description must facilitate the identification and provision of new solutions capable of supplementing existing systems. Most of this work comes under Action Area 4. The National High-Level Group for e-Health will consider suitable forms of action in this area. The Swedish process and information models should adhere as far

Six action areas



Better integration of ICT support systems for health care and social services requires coordinated measures at several levels, as displayed in the adjoining diagram, which also shows the relationship between them. The measures are grouped into 6 action areas. At the highest level, citizens and patients need a web portal in order to access information and services. Healthcare professionals require centralised access to all relevant information and process support systems used in their day-to-day work. Infrastructural support services, such as effective security systems, are needed to ensure that these tools can be used, and can work together. Standards and regulatory frameworks form the basic structures underpinning all ICT support.

as possible to principles and models already existing or under consideration in the EU, and to the international standardisation process.

1. Bringing laws and regulations into line with extended ICT use

e-Health solutions must comply with existing laws and regulatory frameworks. However, one of the obstacles to appropriate ICT use has been the failure of legislation and regulatory frameworks to keep pace with needs of citizens and the services. Ever since computers were introduced into the health care system nearly 40 years ago, existing legislation has been subject

to continual review with the aim of bringing laws and regulations into line with changes in society, including extended and more advanced use of ICT and other new technologies.

The biggest and most publicised issue in the legal sphere has been the need to prevent unwarranted intrusion or the risk of such intrusion into patients' personal privacy. There are a range of legislative provisions designed to protect patient confidentiality and privacy. These include:

- general health care laws, such as the Health and Medical Services Act (*hälso- och sjukvårdslagen, HSL, 1982:763*) and the Professional Activities in the Health and Medical Care Field Act (*lagen om yrkesverksamhet på hälso- och sjukvårdens område, LYHS, 1998:531*)

- laws governing the use of information, such as the Secrecy Act (*sekretesslagen*, 1980:100), the Personal Data Act (*personuppgiftslagen*, PUL, 1998:204), the Care Registers Act (*lagen om vårdregister*, 1998:544) and several other acts concerning registries.
- laws governing different operational aspects and activities in the health and elderly care services, such as the Health Records Act (*patientjournalagen*, 1985:562).

It should be emphasised that e-Health solutions offer better scope for protecting privacy and confidentiality as cases of unwarranted intrusion can be prevented and traced.

NEEDED ACTION

A number of existing laws and regulations designed to ensure secrecy and protection of privacy unintentionally limit the ability to make use of modern e-Health solutions.

- Health and elderly care services rely increasingly on inputs from a range of care units and personnel categories. However, current legislation does not always provide for easy access by relevant, authorised personnel to necessary information about patients.
- Although some laws give patients and their families the right to information and participation in all health and elderly care units, other provisions make it difficult for patients to read their health records or other care documentation from their own computers.
- A set of comprehensive legal rules governing the handling of information are lacking in a number of areas where sensitive information is used. For example, the 50-plus national quality registers now in existence are not regulated by law. A review of these matters is currently under way.

Since the 1992 Ädel reform, which made the municipalities responsible for long-term services and care of the elderly, many older people are able to remain in their homes with support from the social and health and medical care services. Health and social care of the elderly is mainly governed by the Social Services Act (*socialtjänstlagen*, SoL, 2001:453), the Health and Medical Services Act, and the Support and Service for Persons with Certain Functional Impairments Act (*lagen om stöd och service till vissa funktionshindrade*, LSS, 1993:387). The acts differ on a number of points, and decisions on elderly health and/or social care interventions must often comply with two or even three differently worded acts.

Separate requirements govern the handling and documentation of decisions on social and medical interventions. The Social Services Act states that cases

involving social assistance must be investigated and documented, while documentation of health and medical care interventions is required under the Health Records Act. Many elderly care recipients thus have a social services dossier *and* health records. Today, far too much staff time is taken up with documentation; in some cases this is duplicated due to the need to comply with both acts. Both acts contain secrecy provisions designed to protect access to information relating to the individual patient's personal circumstances. This often hinders the transfer of information between care professionals whose activities are regulated by both acts, with the risk that a patient's health and social care needs could go unattended.

The fact that no clear distinction has been drawn between medical devices and medical informatics gives rise to daily uncertainty in the health care sector over allocation of responsibility and security. Many medical devices, such as electrocardiogram machines and X-ray equipment, are linked to the care provider's data network so they can communicate with surveillance systems and EHRs. Information generated by medical devices may also be included in decision support systems of different types. With some applications, this data is transferred from the hospital over the internet.

While meditech manufacturers are responsible for the security of their products' built-in computers and software, responsibility for the security of hospital ICT systems rests with the health care services. Manufacturers' responsibility for the integrity of the data ends as soon as the latter leaves the product. Responsibility for handling internal hospital data then devolves on the health care principal. The issue is further complicated when data is transferred over internet.

ONGOING DEVELOPMENTS

A review of legislation governing the handling of information in the health and medical care sector is currently in progress. The review is the work of the Patient Data Inquiry (*Patientdatautredningen*, 2004:95). The committee, which expects to complete its assignment in 2006, has been instructed to draw up legislation that will provide for greater patient safety while ensuring continued protection of patient privacy. By October 2006, the committee must report on that part of its assignment relating to the need for coherent legislation on the handling of personal data in the health and medical care services, the question of interoperable EHRs, issues concerning quality registers and security issues arising in connection with the above tasks. It is of the utmost importance that the inquiry leads to proposals capable of solving existing problems and bringing about the desired improvements for patients and care services alike.

Other inquiries and reviews aimed at bringing regulations governing the handling of information into line with prevailing conditions are also in progress. One result is the report by the Committee on Public Access and Secrecy (*Offentlighets- och sekretesskommittén, OSEK, SOU 2003:99*) on the new Secrecy Act.

In a society founded on the rule of law, ICT may not be used to handle information in ways that contravene existing law or without legislative authority. At the same time, it is undeniable that legal regulation is failing to keep pace with societal changes, advances in knowledge and rapid technological development. Actors in the care sector must therefore from time to time commission inquiries and make other provisions for the introduction of ICT in anticipation of expected changes in the law. Should these legislative changes fail to materialise, the aimed-for development of process supporting ICT systems can be achieved, though only in part, under existing legislation.

PRIORITIES

- to complete the work of the Personal Data Inquiry and bring proposals for changes in relevant legislation before the Riksdag²
- to bring proposals for changes in the Secrecy Act based on existing reports and comments by referral bodies
- to clarify the regulations governing documentation in elderly care
- to define supervisory responsibility for data transfer between medical devices and ICT systems operated by the health care services.

2. Creating a common information structure

Patient safety requires that medical records follow the patient at all times and that they be accessible to all authorised care providers as and when needed. These data must also be made available for management and follow-up purposes, research and development. All information must be recorded in such a way that only one interpretation is possible. If information is to be a usable resource in the long term, it must be stored electronically, be retrievable and have a uniform, nationally established structure. Information must therefore be placed under a common regulatory framework and form part of a uniform information structure. This will allow ICT systems to handle and exchange information more efficiently.

Patient safety and the ability to follow up care activities are contingent on a uniform information structure based on established terminologies and classifications.

NEEDED ACTION

Achieving a national information structure requires a coherent strategy for coordination and cooperation. Such a strategy must incorporate working methods and provide for the establishment and management of a national library of information structure specifications and standards.

A uniform information structure and established terminologies are essential to the development of the National Patient Summary (Action Area 5), health care guarantee follow-ups and the common data sets needed for health care quality audits. Other important areas are radiology and laboratory results, scheduling, a nationally coordinated health advisory service and the development of a national database for prescriptions

Information structure and information security are closely related. If sensitive personal data is to be transferred and interpreted electronically in the future, patients and care providers must be confident that the information is handled securely. To secure the full benefits of a national information structure while safeguarding other vital interests such as patient privacy and care efficiency, a statutory information security model adapted to the health care services is needed. Such a model will give us a clearly defined minimum standard that will contribute to the secure exchange of personal data and help improve data quality and accessibility.

The information structure must be designed primarily for information exchange between care providers and for collection of data in national databases for follow-up, audit, management and research purposes.

CURRENT DEVELOPMENTS

Only a fraction of the information documented in the EHR is adequately described and can be used as a common resource for the development and improvement of health care.

The government has commissioned the National Board of Health and Welfare to implement measures – in collaboration with the Swedish Association of Local Authorities and Regions (SALAR) – aimed at ensuring that reliable, usable information on health and social care is accessible to citizens, care professionals and decision-makers. The agency has also been tasked with preparing for the introduction of a uniform information structure in the health and elderly care services by drawing up proposals for a national regulatory

2. Swedish parliament.

framework specifying the content, form and structure of information. Under the agency's appropriation directions for 2006, this assignment has been broadened to include responsibility for the coordination of the above issues at national level.

Efforts to establish a single, nationally approved information structure are currently in progress in many countries. SNOMED (Systematized Nomenclature of Medicine) is a standardised, concept-based computer language system utilising scientifically validated terminology for the indexing of the entire medical record, including aetiologies, clinical findings and outcomes. The system has generated a great deal of international interest. It has been developed to support the classification and coding of EHR data. The National Board of Health and Welfare has secured the government's support to begin an assessment of the prospects of utilising SNOMED in Swedish health care.

PRIORITIES

- to coordinate the development of working methods for drawing up information specifications, and to set up and manage a national library of the latter
- to develop an information structure that incorporates established terminologies for interoperable ICT-based tools capable of communicating across operational and organisational boundaries
- to draw up regulations governing information security.

3. Creating a common technical infrastructure

Although care providers are responsible for their own technical infrastructure, they must also be able to communicate securely across organisational boundaries. It is thus essential that they undertake the joint development and management of a national technical infrastructure that will guarantee high standards of quality and security with regard to the transfer of information between care providers and between the care services and other stakeholders such as public authorities and suppliers. The principals must simultaneously ensure the development of their own infrastructure so that local and national infrastructures can work together.

NEEDED ACTION

The national infrastructure will incorporate a common electronic communications 'backbone', i.e. a common national network that can be used for communication across organisational boundaries. This requires tools for finding individuals, people by occupational functions, such as on-call doctors, financial managers or heads of clinics, and ICT systems – in effect an electronic direc-

tory for health care professionals. Parts of the information in the local directories must therefore be accessible by other principals if patients are to be guaranteed continuity of care. It is vital that principals develop their directories using the same basic structure.

Patients often move between different care settings and providers. Access to information and communication must therefore be made secure by using procedures and tools which ensure that only authorised personnel can exchange and make use of the information. The technical infrastructure must therefore include as an essential component common security solutions featuring some form of electronic identification (e-ID). Electronic identification also enables care professionals to access different information systems easily with a single sign-on.

Facilitating the exchange of patient- and care-related information will require common data transfer standards applying not only to the content and structure of information (Action Area 2) but also to the technical structure of data transfer. Standards and regulatory



frameworks for data transfer and communications handling must be established at national level and in close cooperation with bodies engaged in international standardisation work.

It is important that decisions taken at national level concerning where data is to be stored are based on actual information needs. To ensure national access to health care and other important data, a limited amount of information must be kept in central registers. Most of the data registered, however, should be located and managed at local or regional level. To ensure that locally stored information can be accessed, data must be uniformly structured (Action Area 2) and locatable.

Another infrastructural requirement is effective communication between health care services and other actors such as government authorities and the state-owned pharmaceutical retail company, the National Corporation of Swedish Pharmacies (*Apoteket AB*). The health care services are greatly in need of access to the national population register so they can retrieve personal data on patients receiving care. Solutions are also needed in respect of procedures for reporting reasons for sick leave to social insurance offices and to inter-agency communication in connection with rehabilitation and other programmes. It is therefore vital that e-Health solutions such as the EHR system are suitably designed for this type of communication and inter-agency collaboration.

CURRENT DEVELOPMENTS

Over the last five years, Sjunet, the health and medical care services communications network, has been expanded to encompass the health and medical care principals' network. Today, all county councils, some 40 municipalities and a number of private care providers are members of Sjunet. Administratively and in terms of security, however, the network is not yet suitable for use by a large number of small care providers. A Carelink inquiry is currently examining ways of developing Sjunet so that more small care providers can join. It will also submit proposals on the future, long-term management of the network.

A number of county councils have now set up electronic directories for health care professionals. These are used internally by county councils to search for and find contact information on individuals and organisations, opening times, etc. Approximately ten catalogues are also linked up nationally through the health and medical care services' address register (the HSA directory), in which affiliated organisations can display some of the contents to other care providers. The commonly accessible information in the directory is currently being reviewed by Carelink to ensure that the

operations of the municipalities are also represented and that the data is uniformly presented.

A national security solution involving the use of electronic ID cards has been under development for some years. Known as SITHS, which in Swedish stands for secure e-Health, the scheme is based on European security work in this area. Both the HSA directory and SITHS are managed by Carelink. Work is now entering a new phase involving the introduction into a number of operational support systems of e-identification for health and elderly care professionals. Over the next few years, two county councils will introduce SITHS for all personnel concurrently with consolidation work on their ICT structure. Pilot projects are under way in several county councils, in a couple of cases with the active collaboration of their municipal councils.

On 1 October 2005, the Swedish National Police Board introduced a new national ID card. Embedded in the card is an electronic circuit which in the future will be able to carry electronic information – so-called electronic ID services (e-ID) – and thus identify the bearer electronically. The aim is to achieve a national, cross-sectoral e-ID solution capable of ensuring secure electronic identification when e-services are used. This solution can significantly affect citizens' and patients' communication with the health care services.

A newly established government authority, the Swedish Administrative Development Agency (*Verva*), came into operation on 1 January 2006. The agency's responsibilities will include encouraging and initiating operational development in the public administration. Its principal tasks will be to promote a coherent, more efficient government administration and to assume overall responsibility for the 24/7 Agency. Verva will partner the health care and social services in the work of establishing efficient inter-agency collaboration.

PRIORITIES

- to make the necessary financial, regulatory and organisational adjustments needed to enable large numbers of small care providers to join the Sjunet communications network
- to adapt local electronic directories so these can be linked to the national HSA directory in order to obtain a data source for electronic service certificates, among other purposes
- to develop and introduce security solutions based on national electronic ID cards with a view to facilitating secure identification when e-services are used in the health care and social services and other sectors of society.

4. Facilitating interoperable, supportive ICT systems

ICT use varies across and within the operations of health care principals. Variations in ICT use may even occur within a single hospital. ICT-based tools in current use have different purposes and limitations, come from different suppliers and differ in terms of technical structure and design. Standards compliance has been low. These conditions hinder communication between support systems and increase operating costs. This has come about due to the failure of county councils, municipalities and private care providers to effectively coordinate procurement of e-Health solutions. ICT use in municipally run health services is low.

The inability of e-Health solutions to communicate means a good deal of extra work for care professionals, who must be able to handle a number of information systems with different functionalities, user interfaces and log-in procedures. Apart from the fact that information cannot be shared effectively, this creates work environment problems such as stress and irritation.

NEEDED ACTION

If principals and ICT suppliers are to offer a better selection of well-defined e-Health solutions, they must step up their cooperation. Such solutions must support relevant operations, be easy to use and be capable of exchanging information and interacting with other ICT systems in order to guarantee patient safety. They must also be designed and constructed in accordance with established national and international ICT standards.

Principals must simultaneously develop and consolidate their local or regional ICT architecture. This is a precondition for national coordination. ICT architecture is a description of the structure of an ICT system's components and internal disposition, and of the principles governing their construction and development. To simplify data transfer, the ICT systems used by the health care services must be designed and constructed in accordance with common architectural principles jointly established by the services and ICT suppliers.

One way of improving the situation is for the principals concerned to jointly identify operations requiring e-Health solutions and to specify what requirements these solutions will be expected to meet. This would help suppliers to develop ICT-based tools which they know will meet market demands. As the Swedish market is relatively small, there are strong grounds for co-operation on these issues with other Nordic countries and the EU. To preclude the risk of adverse effects on competition between suppliers – which could eventual-

ly restrict the range and quality of the health care services' ICT systems, and thereby have unwanted lock-in effects – such cooperation must ensure the continued dynamic development of new ICT tools.

Improving ICT-based tools also means equipping them with new features and extended functionality. It is now technically feasible to develop expert systems, decision support systems and other knowledge-based support systems at national level. These can give care professionals access to relevant, up-to-date information which can be used in health care work. Development has been comparatively slow and various solutions to the problem of how to use different functions have been adopted. The 50-plus national quality registers used by Swedish health care services constitute a valuable basis for the development of different types of knowledge-based ICT support.

An important current development is the removal of individual functions from a large number of e-Health solutions and the development of general or national common solutions for these functions. Examples include security-related functions such as log-in and consent handling, and information exchange between care units, and between care providers and the community at large, e.g. social insurance offices and the National Corporation of Swedish Pharmacies. This development is contributing to closer interplay between different e-Health solutions.

Joint work on process descriptions, architectures, specifications, regulatory frameworks and compliance with established standards are thus essential to the development of common e-Health solutions. Development of ICT-based tools with built-in decision support systems and communication functions is especially urgent in the following areas:

- description and handling of pharmaceuticals, including communication with the National Corporation of Swedish Pharmacies
- issuing and handling of medical certificates used as a basis for sick leave and communication with social insurance offices
- handling of referrals between the primary health care system and specialist health care
- collaboration when admitting/discharging a patient to/from in-patient care.

CURRENT DEVELOPMENTS

A number of projects have led to national agreements in the form of technical regulations on interoperability in the health care services and to architectural principles governing data transfer between ICT-based tools. The regulations include rules governing technical

interoperability, i.e. system adaptation, and semantic interoperability, which is concerned with data content and structure (Action Area 2). The rules are designed to guide procurement officers responsible for purchasing and introducing new e-Health solutions as well as ICT suppliers.

Electronic medical prescriptions (e-prescriptions) are a strategic puzzle piece in the context of future handling of national medicinal data. This is mainly because the service clearly affords advantages and benefits for all parties concerned. An efficient e-prescription support system and effective procedures for prescribing, dispensing and distributing medicines offers direct, positive benefits for patients and care professionals alike, an important explanation for the large increase in the proportion of e-prescriptions in Sweden. Efforts are now under way to develop ICT-based tools that will improve the medical and financial bases for prescription. Efforts to establish a national organisation for the development, distribution and quality assurance of a medicines information database are also in progress.

The last few years have seen the beginning of an interesting development involving the framing of common specifications that will serve as a basis for the design, construction and supply of e-Health solutions. Examples include common process descriptions, specifications and regulatory frameworks in the pharmaceuticals field. These have served as important elements in suppliers' own development work without hindering competition between them. Several other similarly oriented projects and activities are under way involving *inter alia* ICT-based tools for handling referrals from the primary health care system to hospitals, and medical certificates used as a basis for approving applications for sick leave/sickness benefit and disability pensions. In addition, cooperation between county councils and ICT suppliers in this area is now well established.

PRIORITIES

- to identify e-Health solutions that can be developed jointly, and to draw up common process descriptions and requirements specifications for these
- to agree, in a joint undertaking involving principals, health care units and ICT suppliers, on a set of common principles governing ICT architecture, and to identify and lay down the standards to be followed
- to further develop the regulatory framework on electronic interoperability in the health care services, which is based on identified and established standards
- to develop common quality criteria and regulations governing common user interfaces with a view to creating easy-to-use, secure e-Health solutions
- to develop services designed to facilitate inter-agency

collaboration on issues of ill health, and functions for communication with social insurance offices

- to complete the introduction of e-prescriptions
- to develop nationally coordinated knowledge-based decision support systems to complement existing ICT systems in health care
- to develop a common management system for requirements specifications and regulatory frameworks to ensure effective ICT interoperability in the health care services.

5. Facilitating access to information across organisational boundaries

An increasingly important requirement is the ability to locate and access patient data previously documented in the health care and social services and by different care providers. Such information is needed to improve health care for the individual patient and give us a better understanding of the efficacy of the health care services as a whole.

NEEDED ACTION

There is a need for a set of services that will allow authorised personnel – and, in ordinary cases, patients as well – access to the following information at national level:

- information contained in patient health records and other care-related documentation
- information relating to medicines taken by the patient
- information on analysed and saved laboratory tests
- radiological information including the location of x-ray plates and accompanying medical opinions.

Nationally based services of this kind will require new or amended legislation (Action Area 1). They are also contingent on the adoption of security solutions capable of preventing unauthorised access and contributing to the detection of unauthorised intrusion (Action Area 3).

If health care providers are to provide patients with the best possible care, relevant information in health care records must be made accessible when needed by authorised personnel regardless of where or when this was registered. This will also make it possible to monitor care quality and results in individual cases and for patient groups. Compilations of quality and outcome data can also be used to support decisions, as a basis for transparent audits and in benchmarking.

As patients often have more than one medical prescriber, there is a pressing need for access to all available information on what medicines the patient is or has been

taking. A national medical prescriptions database containing details of all prescriptions issued and medicines dispensed by Sweden's health and medical care services and pharmacies would meet this need. The aim is to ensure better use of medicines through improved decision support data for patients, prescribers and pharmacists.

When prescribing and dispensing, the doctor or pharmacist will be working 'within' the prescriptions database itself. This means that prescriptions, dispensing and any prescription changes will be directly and permanently recorded in the database. Although registration should be mandatory, access by the prescriber or pharmacist to information in the database must require the patient's consent.

Effective follow-up of side-effects and safety issues calls for e-Health solutions that will facilitate and promote reporting to the Medical Products Agency. It is important that the EHR system include functions for reporting side-effects, accidents and near-accidents involving meditech products. Also important in the context of follow-up work in the safety field are the health care quality registers.

CURRENT DEVELOPMENTS

The EHR system is now used in virtually all parts of the primary health care system and in more than half of Sweden's hospitals. Its use in hospitals is expected to increase sharply in the coming years, which will make it easier to locate and exchange information electronically.

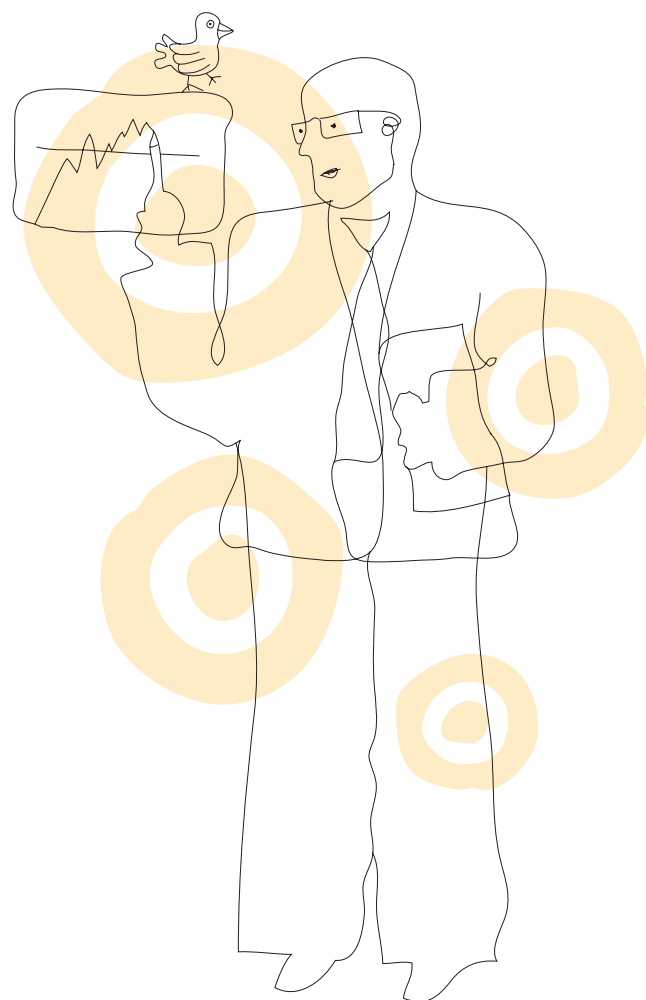
Acting on the government's instructions, the National Board of Health and Welfare has been running a development project (*InfoVU*) in collaboration with SALAR aimed at enhancing collaboration among health care professionals vis à vis the individual patient, improving communication between care providers, and ensuring more effective follow-up based on personal data. The project has laid the groundwork for continued work in this area, inter alia by devising nomenclature, classifications and quality indicators that should be used directly in care documentation. These also help facilitate information supply and follow-up activities. All future initiatives will form part of the normal activities of the agency, the Association and the county councils.

Currently in progress under Carelink's auspices is the National Patient Summary project, a national service for locating and accessing health record data and other health care records no matter where the information has been registered. The information includes details of diagnoses, examinations and treatment carried out. Authorised care personnel will have personal access to

the patient summary subject to informed consent from the patient or her or his family. In due course, patients will themselves be able to access information about their own cases. The project is now in the pilot phase, with services being tested by four county councils.

PRIORITIES

- to feed the results of the InfoVU project into the health care information system
- to complete the ongoing National Patient Summary project
- to lay the groundwork for a national prescriptions database
- to ascertain the technical and practical feasibility of developing national e-services for handling radiological information and laboratory test data.



6. Making information and services easily accessible to citizens

Citizens must have easy, trouble-free and secure access to health care. Everyone should have the security of knowing that they can contact the health care services wherever or whenever the need arises. Citizens need to be able to access and read health-related information, communicate with the health care services in different ways and maintain regular contact with their care provider when needed.

NEEDED ACTION

A great deal of information on health and elderly care is already available electronically on a large number of national, regional and local government websites. This information covers a number of important health care aspects including diseases, symptoms, treatments, medicines, organisation of the health care services and opening hours, physical and electronic addresses, telephone numbers and patient rights. There is also extensive information on the quality and outcome of medical treatment, waiting times and current charges.

However, as the facts are neither easily accessible nor comprehensively presented, there is a pressing need to review, coordinate and adapt the information offered to different patient categories. A vital task in this connection is the design of a common gateway, or portal, to a large, comprehensive body of quality-assured health care information.

Many people today use electronic booking (e-booking) services as a matter of course. The health services also offer this option but not on the scale or in ways appropriate to the needs of patients or their families. As a matter of urgency, therefore, the health care services should take steps to rapidly improve and extend their e-booking facilities, and as far as possible offer a coordinated service with regard to patient testing and treatment. It should be increasingly possible to provide simpler care services electronically as a complement to traditional visits to health care units.

Internet-based services and service have become increasingly common. Keeping up with this trend increasingly presupposes access to a computer and the internet and a degree of familiarity with ICT-based environments. Moreover, these environments must meet certain basic requirements. These include support for speech synthesis and other aids designed to enable visually impaired people to benefit from the contents of a website. If these basic conditions cannot be met, certain groups run the risk of exclusion. Awareness of these and other concerns is thus a vital part of the development of new e-Health services.

ICT use in everyday settings and in working life must serve to safeguard the welfare of the individual. It can also help enhance the quality of life of vulnerable groups in society. ICT can reach people everywhere; it can also accommodate the special functions needed to communicate with vulnerable groups. It can be a medium for addressing a range of issues, such as whether elderly people can continue to live at home, help for people living in remote rural areas, extending the use of telemedicine and providing support and access to the job market for people with disabilities.

CURRENT DEVELOPMENTS

Numerous sources of information on health care can now be accessed via the internet. Examples include the national medical advice and information service (*Sjukvårdsrådgivningen*, formerly *Infomedica*), which offers quality-assured health information free of charge via the internet. The service is financed jointly by the county councils, the National Corporation of Swedish Pharmacies and the government. In addition, all county councils provide telephone-based health advisory services. These are now being linked to the national telephone service, *Sjukvårdsrådgivningen 1177*, allowing callers to contact their local health advisory service on the same telephone number from anywhere in the country. It is in the public interest that these services be expanded, improved and adapted to specific target groups and that clear, easy-to-use information services are developed for use by the citizen as complements to the normal care services.

Today, many patients who have fixed, regular contact with a care provider substitute regular e-mail contact with their care provider for some of their routine visits. As this option is in high demand, it is vital that these services be expanded as rapidly as possible.

On 1 July, the Riksdag approved a proposal requiring the National Corporation of Swedish Pharmacies to draw up a pharmaceutical register containing details of all medicines sold on prescription by pharmacies during the previous 15 months. This amendment to the existing Pharmaceutical Register Act also allows the Corporation to offer customers the option of storing repeat prescriptions in a prescription register. Although registration is compulsory, the consent of the prescription holder is required before the prescriber or pharmacist can read the information. The person whose prescription has been registered will also have direct access to the relevant information in the register either via the internet or on a paper print-out issued by the pharmacy. It is hoped that the pharmaceutical and prescription registers will both be ready for launching in 2006.

The prescription register will include details of repeat prescriptions that have not yet been filled out. Customers will have direct access to the prescription register via the internet or through the pharmacy.

PRIORITIES

- to identify instances where e-Health solutions can be introduced as a complement to traditional ways of communicating with health care services, and to ensure that such services can be used by all individuals of all ages and regardless of physical or technical ability
- to make it easy for citizens to find different health care services and national and local information on health and health care via a common access point – a web portal
- to enable citizens to examine information about their own care and health status via the same common access point
- to provide better arrangements for booking appointments, and to coordinate booking systems in health care. ■

The decision-making process – an overview

The National Strategy for e-Health was drawn up by the National High-Level Group for e-Health. Since its appointment in early 2005 by the Ministry of Health and Social Affairs, the group has invited opinions on the strategy's contents from a wide range of actors and stakeholders in the sector.

Its aim is to ensure that both central and local government authorities approve, adhere to and apply the strategy. The formal decision process begins with the government's decision to approve the e-Health Strategy on the basis of proposals from the Ministry of Health and Social Affairs. The government then sends a communication to the Riksdag to the effect that the strategy now reflects its official position in this area. The government then assigns responsibility for following and implementing the strategy to its agencies, including the National Board of Health and Welfare and the Medical Products Agency.

At regional and local level, the decision to adopt and implement the strategy must be taken separately and independently by each county and municipal council. The formal decision process in this case begins with a proposal from the chief executive officers of SALAR, the joint administrative office of the Swedish Association of Local Authorities (SALA) and the Federation of County Councils (FCC), that the strategy be approved by the governing boards of the latter organisations. It is further proposed that the boards instruct SALAR to seek to prevail on its members, i.e. all county and municipal councils, to adopt the strategy and implement its provisions in their health care services.

If the strategy is to have its intended effect, the decision to adopt it and implement its provisions must be forthcoming from virtually all county and municipal councils.

Action at national level: scope, financing and decision-making

The need for a second stage

The National Strategy for e-Health assumes that a number of issues must be dealt with and solved at national level to ensure that ICT use achieves the intended results and is effective across operational and administrative boundaries, and over geographical distances. There are also economic and other reasons why county and municipal councils should cooperate on ICT-related issues at national level.

A large share of the cost of this cooperation must be borne by the principals themselves. During the strategy development stage it has not been possible for practical reasons to estimate the extent or costs for the work that should take place at national level. These depend on the way tasks are organised and how quickly they are performed. The scope and financing of strategy development work will therefore be the subject of subsequent deliberation and decision within and between the county councils and municipalities. It will also be necessary to agree on decision-making procedures and on ways in which the results of the group's work can be translated into action. These issues will therefore be dealt with in a second stage of the strategy development process.

Financing the joint undertaking

The basic principle underlying our decentralised health care system is that the principals – the municipalities

and county councils – are wholly responsible for the development and financing of their operations. However, they are dependent for the financing of their undertakings on taxes and central government grants. This in turn involves regular discussions with central government. The government must also compensate for any economic effects arising as a result of measures entailing greater commitment or higher levels of ambition in the county and municipal councils' statutory or mandatory undertakings. The government may be also expected to contribute to the financing of measures that generate economic benefits or improvement for citizens in other respects.

The central budget appropriation frame for local government financial equalisation has included funds from the general government grant since 1 January 2005. The purpose of the appropriation is to ensure that county and municipal councils operate under equally sound financial conditions. It also serves as an instrument for financial regulation of the local government sector. To ensure that service and quality levels in the sector are maintained, the appropriation has been strengthened significantly in recent years, and further increases have been announced.

The main points on which the National Strategy for e-Health is based are that ICT is to be used to develop, improve and adapt health care services to new conditions in society. This means it is necessary to remove any obstacles to the unimpeded operation of the health care services across county or municipal boundaries and operational divisions, and over geographical distances. Although a range of ICT-related issues need to be solved at national level if health care is to function efficiently and effectively, basic responsibility for implementation, development and financing of health care operations rests with the principals. This means they are jointly responsible for most of the financial costs for work that needs to be done at national level.

Should the government want the development and reform of the health care services to go further or proceed more rapidly than the principals believe is warranted or what they feel they can achieve, the question of negotiations with the government on incentive funds naturally arises. It should be noted that some of the changes ensuing from the National Strategy for e-Health, including more rapid introduction of important e-Health solutions and higher levels of ambition in terms of information supply, are borderline cases for legitimate requests for government incentive funds. The government's desire for more rapid development and change in the health care sector, based on investment aimed at promoting greater ICT use, can thus justify requests for incentive funds. Consensus among

the principles and a common desire to implement the changes in question are likely to improve their chances of negotiating and reaching agreements with the government on this issue.

The second stage

In the second stage of the National Strategy for e-Health project, SALAR will in 2006 open talks with the county and municipal councils following decisions reached by the governing boards of SALA and FCC. Items on the agenda will include the extent and financing of and decision-making procedures for the work that needs to be undertaken at national level. This will not only involve tasks in connection with the National Strategy for e-Health, but also ICT-related work in the health care sector which should be undertaken at national level for financial or other reasons.

This stage will also be concerned with the possibility of negotiating government incentive funds for speeding up or otherwise intensifying work at national level. A position on the planning, implementation and financing of future work in connection with ICT issues at national level will be taken by the National High-Level Group for e-Health on the basis of the outcome of Stage 2. A report is to be presented by March 2007.

Follow-up

It is important for a number of reasons to follow up the impact, practical application and outcome of the National Strategy for e-Health. Initially, this will mainly involve following up strategy implementation and application, and determining what measures will be needed to promote a greater understanding of the need for such a strategy.

At a later stage, follow-up work will have to be broadened to include the identification of problems relating to the practical application of the strategy, at which point any clarification or modification needs will be addressed.

The necessary follow-up work will be undertaken by several bodies. The Ministry of Health and Social Affairs, the National Board of Health and Welfare, the Medical Products Agency, the National Corporation of Swedish Pharmacies, SALAR and Carelink all have – each in its own area of operation – a responsibility and the need to follow up the impact, practical application and outcome of the strategy.

As the above actors are jointly involved in ICT-related issues as members of the National High-Level Group for e-Health, the latter bears collective responsibility for all follow up activities. ■

The main aim of the National High-Level Group for e-Health is to bring about the necessary consensus and coordination on ICT issues and thereby enable ICT to be used to develop and enhance the efficiency and effectiveness of the health care services. Given the structure of the health care system and the division of competencies within it, the introduction and application of the National Strategy on e-Health will require the participation of national organisations. A brief description of the most prominent of these bodies – with emphasis on their responsibilities in the ICT field – is set out below. The following section only deals with the organisations represented in the National High-Level Group for e-Health. Their tasks in each case are vital to the strategy's introduction, realisation and functioning.

County councils, municipalities and private care providers bear primary responsibility

Primary responsibility for health care in Sweden's decentralised care system lies with the county and municipal councils, the principals for health care services financed by public funds. Their responsibility includes the provision of adequate care services and the obligation to develop, quality-assure and finance all care activities. Both county and municipal councils engage the services of private health care companies to a greater or lesser extent. There are also a small number of wholly privately financed providers. Private care providers responsible for their own financing and acting as legal entities are also classified as principals.

As local self-government bodies, county and municipal councils must make their own independent decisions

with regard to how and for what purpose ICT is to be used, and themselves procure or develop the e-Health solutions they opt for. Private care providers also decide on their own ICT use in the same way. However, they must comply with the information handling and reporting requirements set out in their agreement with their county or municipal council. This means that cooperation on and coordination of ICT-related issues involving principals on the one hand and private care providers on the other must take place on a voluntary basis.

Overall responsibility rests with the government

Ministry of Health and Social Affairs

The Ministry of Health and Social Affairs is one of the nine ministries forming part of the Swedish Government Offices. Its areas of responsibility include health and medical care, public health, social insurance, policy for the elderly, child policy, social services and disability policy. The ministry's primary duty is to help the government govern Sweden and carry out its policies. The ministry supplies the Government with decision support data and works to ensure that decisions are implemented. It frames objectives for the health care and social services, makes laws governing their implementation and monitors and follows up operations.

An important task is to direct and follow up the activities of central agencies that fall within the Ministry's sphere of responsibility. The government sets out objectives and guidelines for and allocates resources to these agencies but cannot instruct them on how to pro-

ceed as regards the application of laws or the handling of matters that come before them. Important issues of current interest may be dealt with by special committees of inquiry appointed by the government.

The ministry takes an active part in international exchanges of information relating to e-Health. As the scope for greater patient mobility increases, so will the need for the effective exchange of health care-related information across national borders. Moreover, the potential for strengthening national efforts in the health and medical care sector through cooperation in this area is considerable. By bringing back and disseminating internationally available know-how and expertise in the development of ICT-based tools and their use in the health care sector, the ministry helps ensure that e-Health solutions are more cost-effective and based on better decision-support data than would otherwise be possible. The ministry is engaged in a number of international collaborative undertakings relating to e-Health, primarily in the EU and under the auspices of the Nordic Council of Ministers. It also closely follows efforts initiated by global actors. A global e-Health action plan has recently been presented by the World Health Organization (WHO). International exchanges of experience could be of significance for the government's future priorities in this area.

National Board of Health and Welfare

The National Board of Health and Welfare is the national expert body and supervisory authority in a range of policy areas including social services, public health protection, infectious disease control and health and medical care. The agency thus affects the actions of principals and care professionals through its standardisation work, supervisory duties and knowledge communication initiatives. In recent years, the agency's responsibility for supporting quality development in health care at national level has become increasingly clear. Individually based follow-up supported by quality indicators have attracted increasing attention. The agency and SALAR have collaborated in the development of knowledge bases, support systems and methods under the InfoVU joint project. They have also identified the legal, ICT-related and other conditions and requirements that must be met if the goal of "reliable, useful information on health and elderly care services, and easy, trouble-free access for citizens, fellow employees and decision-makers" is to be met.

The agency was commissioned in its appropriation directions for 2006 to prepare to assume overall, national, strategic responsibility for ensuring that individualised patient data is more precisely, i.e. unambiguously, formulated, accessible and capable of being followed up. This will require a common national

information structure, uniform nomenclature and classifications, nationally established quality indicators, and more rational and appropriate health care documentation procedures. A common national information structure and standardised terms and concepts will facilitate communication between principals and is a precondition for the compilation and transfer of information between ICT systems. This will in turn contribute to increased patient safety, facilitate transparent audits and comparisons of health care processes and outcomes and provide support data for quality development.

Medical Products Agency

The task of the Medical Products Agency is to ensure that the individual patients and the health and medical care services have access to safe, effective, high-quality medicinal products, and that these are used in a rational and cost-effective manner. The agency also promotes the safety and quality of natural remedies such as traditional plant-based medicines, and is responsible for the surveillance of medical device manufacturers and their products. Main tasks include:

- approval of human and veterinary medicinal products
- monitoring clinical trials
- follow-ups, including quality control, inspection, side-effects and safety issues
- information
- registration of traditional, plant-based and homeopathic medicines and monitoring of cosmetics, narcotics and technical spirit
- monitoring of medical devices.

The agency plays an active role as a standard-setter, inspection and monitoring body and discussion partner in the development of new medicinal products. During the development of a medicinal product, the agency monitors the necessary clinical trials to ensure that these are safe and scientifically proven.

Once a medicinal product is approved, the agency monitors its use, provides information and issues treatment recommendations to prescribers in the health and medical care services. It is particularly important to continually monitor medicinal products for possible side-effects and, when necessary, take appropriate measures. This also applies to medicines intended for animals.

Since Sweden joined the EU, the agency has followed the rules and procedures applied in the European system governing the approval of medicinal products.

Other actors and stakeholders at national level

The Swedish Association of Local Authorities and Regions

On 1 January 2005, the Swedish Association of Local Authorities (SALA) and the Federation of County Councils (FCC) established a new entity with joint administrative units: the Swedish Association of Local Authorities and Regions (SALAR). In 2007 the two organisations will merge and form a new, joint federation with the same name.

The new Swedish Association of Local Authorities and Regions will represent the interests of Sweden's county and municipal councils. SALAR's main tasks are to:

- develop local self-government with the accent on freedom of action and broad-based citizen support
- actively safeguard members' interests at national and international level
- act as an employers' organisation
- promote and develop collaboration between and among its members
- contribute competently to the development of its members' operations
- provide a national political arena for local government policies
- be a meeting place for its members.

During the second stage of development of the National Strategy for e-Health, SALAR will campaign for the adoption and implementation of the strategy by all county and municipal councils. It will also take part in deliberations with SALA and FCC on the strategy's orientation, priorities, scope, financing and decision-making procedures.

The National Corporation of Swedish Pharmacies (Apoteket AB)

The task of the National Corporation of Swedish Pharmacies in relation to the aims of the National Strategy for e-Health and their realisation is to continue its efforts to develop a safe and secure process for the delivery of medicinal products to the patient. The point of departure for this undertaking is the national pharmacy system with its unrivalled access to medical products, knowledge and expertise. Apoteket is a national information hub as regards medicinal products, for the individual as well as for the health and elderly care services. This enables the services to assume greater responsibility for patient safety.

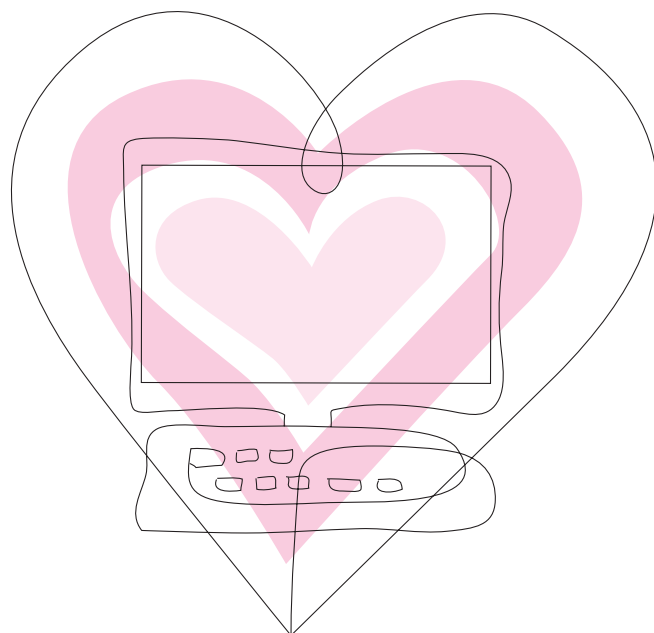
A common delivery process – from prescribing to the physical or virtual prescription to dispensing – not only

makes it easier for all involved to systematically pass on viewpoints and comments from the customer/patient on pharmaceutical use, but also provides more comprehensive support data for each stage of the process. The knowledge generated from the process can be used by all actors involved, including the customer/patient, to improve the use of medical products. A common process gives all actors an incentive to effect improvements to the process as a whole, as opposed to each separate organisation.

Carelink

Carelink was founded in 2000 by the Swedish Association of Local Authorities and Regions (then the Federation of County Councils and the Swedish Association of Local Authorities respectively), the Association of Private Care Providers and the National Corporation of Swedish Pharmacies. Its operations are supported by the National Board of Health and Welfare through a collaborative agreement. Carelink is a member-based organisation open to county and municipal councils and private care providers. Its members have access to the development work currently in progress and are free to contribute their own expertise and experience.

Carelink promotes the development of Sweden's health and elderly care services by initiating, developing and managing national e-Health solutions in collaboration with its members and other stakeholders. The operations of Carelink AB are managed by a special interest group composed of representatives of county and municipal councils, private care providers and the National Corporation of Swedish Pharmacies.



Carelink offers the following:

1. Strategic ICT guidance
to seek to create a concrete national strategy in dialogue with stakeholders, and to plan and manage national ICT initiatives in the health and elderly care services (target group: management)
2. Development
to direct and coordinate national initiatives and development projects aimed at developing efficient and effective e-Health solutions (target group: citizens and health and elderly care professionals)
3. Management
to securely establish the value of developed national solutions through secure functionality, accessibility and continuous development (citizens and health and elderly care professionals)

Carelink's overall goal is to promote efficient and effective e-Health solutions in the health and elderly care services and thereby help to:

- benefit society through better public health
- benefit citizens through better accessibility and safer care
- benefit care providers by helping to improve the quality and efficiency of their operations.

National High-Level Group for e-Health

The government and the Swedish Association of Local Authorities and Regions made a joint commitment in 2005 to closer national collaboration on development of ICT in the health and social care sector. The agreement emphasised the key role of ICT in the development of the health care and social services, and pointed to the need for nationally coordinated action. The mandate of the High-Level Group has now been extended. In 2006, the High-Level Group will assume responsibility for informing stakeholders, care professionals and the general public about the content and importance of the National Strategy for e-Health, following up its implementation and securing broad-based support for its provisions. It will also initiate a strategy discussion on decisions that need to be made at various levels if the strategy objectives are to be achieved.

The group's aim has been to develop the strategy in open dialogue with many of the health care sector's key stakeholders in order to benefit from existing knowledge and experience in this area. This will increase the

likelihood of achieving the strategy objective of meeting the needs of the sector as far as possible. A broadly constituted reference group composed of experts and industry representatives was accordingly created in the autumn of 2005. The group will act as an advisory drafting body for the High-Level Group. The reference group includes representatives from other ministries, committees of inquiry, government agencies, the research community, private care providers, the pharmaceutical industry, ICT suppliers to health care and health care professionals' national organisations.

A list of the participants in the National High-Level Group and its reference group is included in chapter 7. ■

Participating actors and stakeholders

National High-Level Group for e-Health

Ministry of Health and Social Affairs
 Swedish Association of Local Authorities and Regions
 National Board of Health and Welfare
 Medical Products Agency
 National Corporation of Swedish Pharmacies (Apoteket AB)
 Carelink

Reference Group

Association of Private Care Providers
 Committee on Public Sector Responsibilities
 Health Care Forum
 Karolinska University Hospital
 Knowledge Foundation
 Ministry of Finance
 Ministry of Industry, Employment and Communications
 Patient Data Inquiry
 Royal Swedish Academy of Engineering Sciences
 Swedish Agency for Networks and Cooperation
 in Higher Education
 Swedish Association of Health Professionals
 Swedish Association of the Pharmaceutical Industry
 Swedish Federation for Medical Informatics
 Swedish Government 24/7 Commission
 Swedish Governmental Agency for Innovation Systems
 Swedish Government Strategy Group on IT Policy
 Swedish Medical Association
 Swedish Medtech
 Swedish Municipal Workers' Union
 Swedish Pharmaceutical Association
 Swedish Social Insurance Agency
 Swedish Society of Nursing
 Swedish Standards Institute (SIS)
 Uppsala University Hospital

The National High-Level Group for e-Health has drawn up and agreed on a set of basic principles for national collaboration on ICT development in the health care sector. These are intended to support the continued development and renewal of the health care and social services. The Group comprises representatives of the Ministry of Health and Social Affairs, the Swedish Association of Local Authorities and Regions, the National Board of Health and Welfare, the Medical Products Agency, the National Corporation of Swedish Pharmacies (Apoteket AB) and Carelink.

With the National Strategy for e-Health Sweden has also met the challenge set out in the European Commission's Action Plan for e-Health: "Each Member State is to develop a national or regional roadmap for e-Health by the end of 2005."

The National Strategy for e-Health can be downloaded from the Swedish government website: www.sweden.gov.se/health

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Swedish Association
of Local Authorities
and Regions

