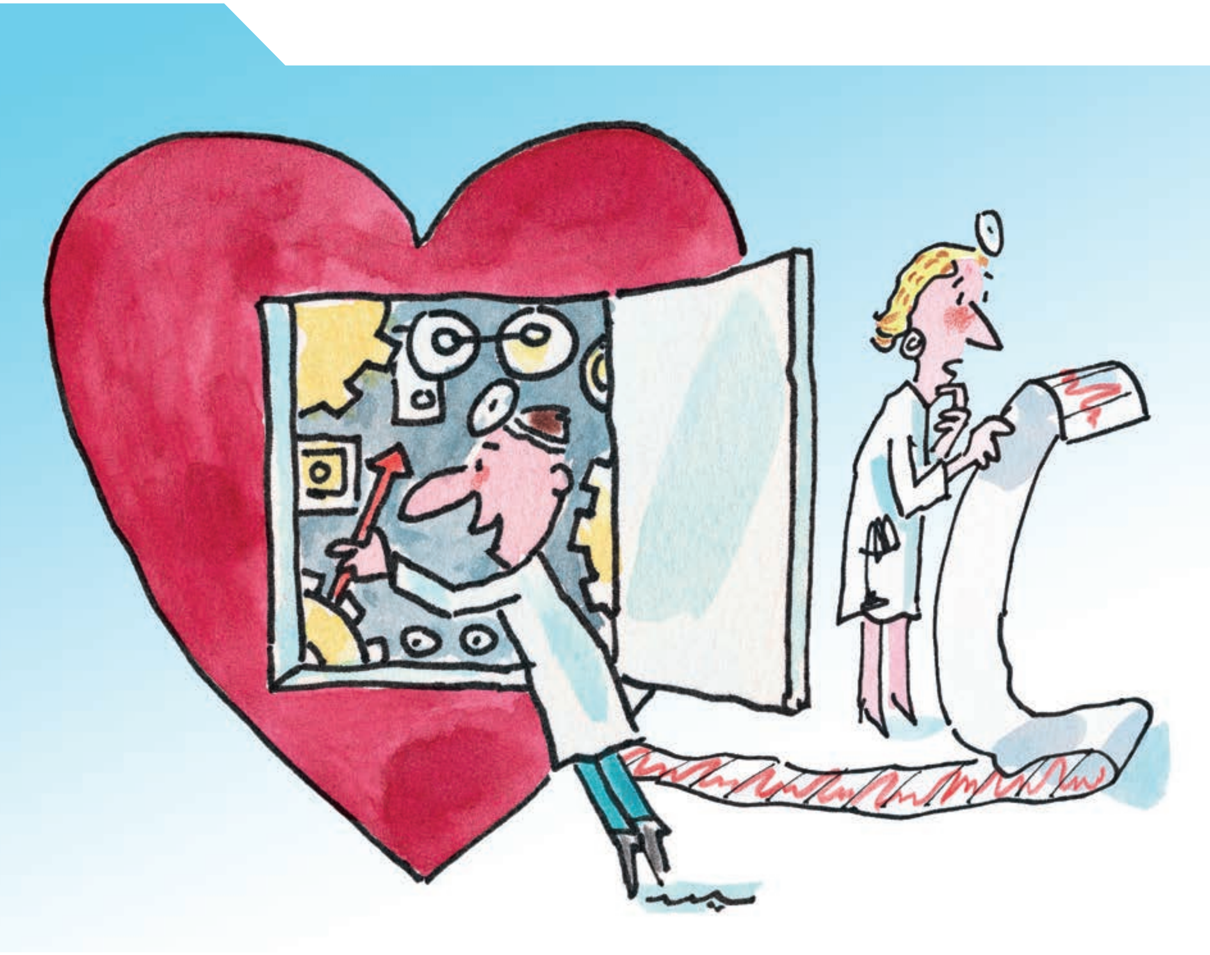
OECD Reviews of Health Care Quality

SWEDEN

RAISING STANDARDS



OECD Reviews of Health Care Quality: Sweden 2013

RAISING STANDARDS

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Foreword

This report is the fourth of a new series of publications reviewing the quality of health care across selected OECD countries. As health costs continue to climb, policy makers increasingly face the challenge of ensuring that substantial spending on health is delivering value for money. At the same time, concerns about patients occasionally receiving poor quality health care have led to demands for greater transparency and accountability. Despite this, there is still considerable uncertainty over which policies work best in delivering health care that is safe, effective and provides a good patient experience, and which quality-improvement strategies can help deliver the best care at the least cost. *OECD Reviews of Health Care Quality* seek to highlight and support the development of better policies to improve quality in health care, to help ensure that the substantial resources devoted to health are being used effectively in supporting people to live healthier lives.

In many ways, Sweden's health and long-term care systems are regarded as exemplars to be emulated across the OECD. Yet an ageing population, increasing expectations of service users and diversification in how, where and when care is delivered are testing these systems' ability to continue delivering high quality care. To meet this challenge, Sweden needs to develop richer information systems, particularly by establishing a broader range of quality indicators in the primary and community care sectors, and explore ways of linking data from different sources to capture a more comprehensive picture of the patterns of care for individuals. A clearer role for central government is also needed, focusing on developing standards, building the evidence base and sharing knowledge. Local governments are the main providers of publically funded care: strengthening co-ordination and integration across services, encouraging continued innovation in how county councils and municipalities design and deliver services, and sharing learning effectively will all be vital in securing high quality and continuously improving care.

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Acronyms and abbreviations

ADL	Activities of daily living
ALCOVE	Alzheimer Co-operative Valuation in Europe
ANESM	National agency for assessing organisations providing long-term care
ASCOT	Adult Social Care Outcomes Toolkit
BPSD	Swedish Registry on Behaviour and Psychiatric Symptoms in Dementia
CCM	Chronic care model
COPD	Chronic obstructive pulmonary disease
CPD	Continuous professional development
CSI	Customer satisfaction index
CVD	Cardiovascular disease
DAAS	San Francisco Department of Aging and Adult Services
EU	European Union
GDP	Gross domestic product
GHQ-12	General health questionnaire
GNP	Geriatric nurse practitioner
GP	General practitioner
GTT	Retrospective Medical Record Review
HAS	Haute Autorité de Santé (France)
HSAN	Agency deciding on disciplinary measures in the event of complaints or possible malpractice
IHSCB	Inspection of Health and Social Care Board
IT	Information technology

KOLADA	Municipal and county database on social services
LDL	Low density lipoprotein
LTC	Long-term care
MPA	Medical Products Agency
NBHW	National Board of Health and Welfare
NHS	National Health Service
NICE	National Institute for Health and Care Excellence (United Kingdom)
NNT	Number needed to treat
OECD	Organisation for Economic Co-operation and Development
PCMH	Primary care medical home
PROMS	Patient Reported Outcome Measures
PYLL	Potential years of life lost
QOF	Quality and Outcomes Framework
RKA	Council for the Promotion of Municipal Analyses
SAHFE	Standardised Audit of Hip Fractures in Europe
SALAR	Swedish Association of Local Authorities and Regions
SBU	Swedish Council on Technology Assessment in Health Care
SEK	Swedish kroner
SMA	Swedish Medical Association
SNOMED C	Systematized Nomenclature of Medicine Clinical Terms
SVEDEM	Swedish Dementia Registry
SWEDAC	National Accreditation Authority
SWEDEHEAR	National Quality Register
VHI	Voluntary Health Insurance

Executive summary

This report reviews the quality of health care in Sweden. It begins by providing an overview of the range of policies and practices aimed at supporting quality of care in Sweden (Chapter 1). It then focuses on three key areas particularly relevant to elderly populations: strengthening primary care in Sweden (Chapter 2), better assurance for quality in long-term care (Chapter 3), and improving care after hip fracture and stroke (Chapter 4). In examining these areas, this report seeks to highlight best practices and provides recommendations to improve the quality of care in Sweden.

The Swedish health care system is often considered as a model for other countries to emulate, both because of its excellent outcomes compared to OECD countries and several well-developed strategies to assure and improve the quality of its health care. Over recent decades, Sweden has instituted an impressive number of quality assurance mechanisms, including measurement of performance, several indicators on quality of care and open peer-to-peer comparison. There are nevertheless opportunities to modernise Sweden's quality architecture, particularly by developing a richer information infrastructure around primary and community care. At the same time, the central authorities should be given a more defined role in *assuring* the quality of services, by developing clear quality standards. The need to achieve greater co-ordination between health care services is also of paramount importance to assure the quality of care of an ageing population.

In Sweden, the ***quality management system*** is advanced. It is based on a wide range of national guidelines and patient registries, and relies on an extensive system of reporting based on quality and efficiency indicators. Sweden also has a long tradition of involving users through the measurement of patient experiences to improve quality of care. In the context of population ageing and in response to its recent policy reforms, however, more could be done to broaden the current information system in developing new quality indicators, data standards and classification systems for both the primary and long-term care sectors. At the same time, existing quality strategies should be complemented by a formal system of performance evaluation for both health professional and health care organisations working in these sectors. Strengthening re-certification of health professionals and accreditation of health care organisations are key components to fully assure and improve the quality of care.

Although the ***primary care sector*** in Sweden is high performing and well organised, it faces a number of challenges related to the increasing prevalence of chronic illnesses. Primary care providers are ideally placed to meet the needs of patients with one or more long-term conditions, and to act as a care co-ordinator across complex clinical pathways. A stronger data infrastructure is also necessary before achieving the role of co-ordinating the care of elderly patients with complex needs. In particular, Sweden should develop a standardised primary care information infrastructure and to develop benchmarking activity to work toward quality improvement in primary care. To go further, Sweden also needs to enhance the role of secondary prevention within primary care sector and thereby insure that doctors and nurses have adequate training to provide care for patients with complex needs.

In Sweden, quality of ***long-term care*** is regarded as a priority. Whilst Sweden's long-term care policy is among the best internationally, there is room for improvement around assessing and assuring the quality of long-term care. Despite significant efforts to foster the collection of data and make publicly available quality indicators for elderly care, there is still inadequate measurement of quality in the long-term care sector. To fill existing gaps, central government should devote attention to the development of additional quality indicators (such as the rates of falls and injuries or pressure ulcers) and standards around long-term care. Better use of existing information is also required to track patient needs and experiences in order to make progress toward providing co-ordinated care. The latter is critically important for elderly patients with complex needs who may be less able to navigate the health care system. The development of new practical systems to foster sharing of information between providers and clearer lines of accountability would facilitate greater care co-ordination.

Finally, ***post-acute care after stroke or hip fracture*** is a good measure of the degree to which Swedish health care systems are able to provide a complex and tailored array of services in the face of sudden and unexpected disability. Compared to the acute phase of care in hospital, there is a distinct lack of guidance of quality monitoring in place once a patient is discharged from hospital. This points to the need to develop a richer information structure, clear quality standards and comprehensive guidelines for community-based care. Developing the relevant quality registers to capture a fuller set of measures of post-discharge care, including patient experiences, would facilitate monitoring quality across the entire patient pathway. As well as extending the quality information frameworks into the post-acute phase, there is a need to drive closer co-operation between health and social care services and pay particular attention to achieving secondary prevention for these common conditions.

In summary, Sweden’s generous health care system performs well on most quality indicators but like all other OECD countries, it faces a number of challenges including the need to establish stronger information systems through the development of new quality indicators, standards or systems for primary and long-term care sector. This is critically important for providers and authorities to improve the quality of health care, as well as for patients to enable choice and foster quality-based competition among providers. Given Sweden’s ageing population, concerted effort should be made around better co-ordinated care between primary, secondary and community health services.

Assessment and recommendations

Sweden's generous health and long-term care systems are regarded across the OECD as models to be emulated. Several of the indicators of health outcomes and quality of care are better than the OECD average and citizens enjoy good access to care, while health expenditure is only slightly above the OECD average of 9.3% in 2011. However, the combination of an ageing population alongside increasing expectations of service users for seamless care within and across the health and long-term care sectors, are testing whether these systems can continue to deliver effective, safe and patient-centered care. Long-standing emphasis on local governance and reforms since the 1990s seeking to drive up performance in Sweden´s health and long-term care systems through patient choice and provider competition have resulted in a "light touch" governance model, these approaches must now be balanced against the need to deliver quality in a consistent and transparent manner and assure whole pathways of care.

The Swedish health and long-term care systems are largely publically financed and locally managed. Responsibility for design and provision of health services falls largely to Sweden's 290 municipalities, 21 regions and county councils, while central government has traditionally limited itself to a steering or guiding role. Primary care is staffed by highly trained, multidisciplinary teams, and care for the elderly is delivered in people´s own home as far as possible. In line with other OECD countries, the average length of stay in hospital is falling – from over seven days around a decade ago to 5.5 days today – meaning that community health systems are being asked to further increase the amount of preventive and curative care they provide.

Governance around health care quality is well-established and based largely on providers' self-regulation, measurement of performance (including through Sweden's numerous disease-based quality registers) and comparison with peers. Recently, the use of market incentives has increased. Private and social enterprises are allowed to provide primary care, community care and long-term care, in an effort to drive up quality and efficiency through competition. Around one third of primary care centres are privately owned and just under 20% of elderly people receive home care through private providers.

A key ambition of Sweden is to have health and care systems that maintain people's well-being and independence as fully as possible as they age: preventing ill-health wherever possible, responding promptly and comprehensively when sudden events occur and offering co-ordinated, personalised care for the elderly as their needs evolve over time. Assuring the quality of these systems is central, especially when they are generously publically funded, as in Sweden. In 2010, the government invested 140 million Euro in an effort to improve the co-ordination of care for elderly people and strengthen quality registries. Yet Sweden's rapidly diversifying service delivery models and rising public expectations call into question whether the quality architecture that currently exists is able to provide such a quality guarantee and a number of challenges remain to be addressed:

- A rapidly evolving policy context and rising public expectations means that Sweden's quality governance style of quality assessment, peer-to-peer comparison and self-regulation, which has served care systems well up to now, should be reformed so that it can assure – as well as measure – the quality of care.
- Even at the level of quality measurement, the current data infrastructure is unable to give a sufficiently detailed or informative picture of the quality of primary care or long-term care for the elderly.
- The quality-argument underpinning choice and competition reforms is weakened by the fact that service-users do not have sufficient quality-based information upon which to base their choice of provider.
- There is a risk that a market place of providers offering disparate individual services may threaten geographic equity of care or could discourage the co-ordination and integration of care for those with complex care needs.
- The IT environment underpinning primary and long-term care for the elderly is characterised by a lack of inter-operability between systems, information standards and classifications, hampering the sharing of information and patient records across providers. Additionally, Sweden's quality registers tend to exist in isolation, with little cross-talk between them.

- Secondary prevention needs improvement: less than a quarter of all diabetic patients, for example, have adequately controlled blood pressure with a two-fold variation across counties; in older women who have suffered a fracture, less than 1 in 6 receive appropriate preventive therapy to reduce the risk of another fracture, with a range of 7-22% across counties.
- Communication between providers and co-ordination are areas where Sweden compares unfavourably with other OECD countries.

Responding to these challenges will require further reform. This review makes recommendations for how Sweden can extend and deepen the quality architecture it has in place to ensure that its quality systems remain fit for purpose to respond to the needs of an ageing population in a rapidly evolving political and social context. In particular, Sweden needs to develop richer information systems, especially by establishing a broader range of quality indicators in the primary care and community health services, as well as define a clearer role for the central government that focuses on developing standards, building the evidence base and sharing knowledge. The rest of this chapter makes a more detailed assessment and set recommendations for three areas of care particularly relevant to elderly populations: primary care, long-term care and post-acute care after stroke or hip fracture.

From quality assessment of single services to quality assuring whole pathways of care

Sweden has a strong base of quality strategies in place

Sweden has, by international standards, a highly evolved health care quality architecture. The overall governance model applied to health care quality has traditionally sought to give professional groups, institutions and localities as much autonomy as possible in monitoring and improving their own standards of practice. The model is underpinned by rich use of information and feedback: Sweden has an impressive track record around measuring and publishing indicators on the quality of care, both at provider level and at population level. In particular, a broad range of national quality registers have been developed covering defined diagnostic areas. Counties or municipalities will often extend these to focus on specific local interests.

The incentive provided by publication of performance measures and open comparison with peers is another key element. At the aggregate level, the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SALAR)'s regular publication of counties' performance across more than 150 indicators of health care quality and efficiency, showcases a breadth and depth of transparent public reporting that few other OECD countries can currently emulate. Financial incentives distributed from the central government to local governments also form part of a quality architecture that emphasises local decision-making, rather than control and regulation from the central government.

A variety of quality improvement methods borrowed from industry has also been applied. In particular, measures of the user experience are well-established, involving regular National Patient Questionnaires, Population and Patient Surveys and a variety of patient reported outcome measures included in the quality registers. Significant efforts are made to involve users in quality improvement efforts, publishing public-oriented summaries of quality reports alongside policy-oriented technical versions and including formal representation from patient groups when planning local services, for example.

Yet the quality architecture currently in place is not fully aligned to Sweden´s rapidly evolving policy context

Despite the breadth and depth of this health care quality architecture, the evolving health and long-term care needs of Sweden's elderly population as well as recent reforms challenge whether it remains entirely fit for purpose. While patient choice and provider competition reforms have been motivated by a concern for quality, convincing demonstration of a quality dividend will prove challenging given, for example, the lack of quality related data around home care services for the elderly.

Furthermore, there are concerns that encouragement of competition across providers may raise risks of geographic inequity and could discourage integrated care and information sharing for those with complex care needs (who are also often the service users that are least able to exercise informed choice). Around 20% of primary care doctors in Sweden report that they receive the information necessary to manage the patient within 48 hours of discharge from hospital, compared, for example, to nearly 70% in Germany. Sweden performs consistently worse in comparison to OECD peers across a series of measures of a patient's experience, such as feeling adequately involved in decisions made about them or being given information in an manner that is easy to understand (although small sample sizes may limit the comparability of this data). Additional safeguards may be needed, therefore, to ensure that particular patient groups are not left behind in terms of patient-centered and integrated care as a result of recent reforms.

Richer and more effective information systems are needed

Developing better information systems around performance and outcomes is perhaps the foremost priority for Sweden's primary and elderly care services. Whilst Sweden has used information on performance and outcomes in hospital care in a particularly rich way, the data infrastructure is currently not equipped to deliver the information needed to assure and improve the quality of primary care and elderly care outside of the hospital sector. Reforms are needed along three lines: developing new quality indicators in primary and elderly care; better using the quality indicators that exist; and developing comprehensive data standards, classification systems and data sets for primary care and long-term care.

New quality indicators are needed by patients to exercise choice between competing providers in a more informed manner, by providers for quality improvement through peer to peer comparisons, and by the authorities to assure quality across the market place and to measure progress towards the goals of integrated and co-ordinated care:

- Sweden needs to follow other countries' leads in encouraging or requiring its primary care sector to open up to greater scrutiny of its activity and outcomes. A range of validated quality indicators have become well-established in the United Kingdom and Israel (such as the proportion of diabetic patients with adequately treated blood pressure or cholesterol), yet use in Sweden is very limited – primarily because of a lack of standardisation of primary care data systems. Sweden should invest in a standardised primary care information infrastructure and encourage a culture of benchmarking activity and outcomes to support patient choice, quality improvement and quality assurance.
- In the long-term care sector, there are too few validated quality indicators. While pilots are underway on indicators around medication safety and avoidable hospital admissions, Sweden should strengthen efforts to identify and validate additional quality indicators such as rates of falls and injuries, pressure ulcers, infections and patient/carer experiences or reported outcomes. It will be essential to ensure that any new indicators are actionable, that is, that agreed lines of accountability are drawn to those who are able to address any shortcomings that the indicators reveal.

Reforms are also needed to how Sweden uses the information infrastructure currently in place. Although the Swedish health care sector has advanced IT systems, and all primary care providers have electronic patient records, several different IT systems are in use with an overall lack of uniform information standards and classifications. County councils, regions and municipalities use different information systems and have adopted different IT solutions that are not always compatible across or even within the same organisation and levels of care. Hence, the IT environment, with stand-alone systems and a lack of inter-operability, does not adequately support co-ordination and the sharing of information or patient records across providers. Sweden has taken steps to identify a standard, basic dataset that can be read across diverse IT systems and efforts in this direction should be stepped up in order to support the goal of integrated care. Special effort should be made to include providers of long-term care for the elderly and home nursing care, as these sectors have historically made relatively light use of IT.

Additional scope for reform concerns Sweden's extensive set of quality registers. Most still rely on data submission as a separate, subsequent step to the clinical encounter, rather than pulling necessary information automatically from consultation notes (electronic or otherwise). This is not only an inefficient use of clinicians' time but introduces the possibility of data omission or error. Ensuring that quality registers and clinical IT systems are as compatible as possible (in terms of structure, terminology and content) will probably encourage greater data submission. It also offers a means to validate and quality assure the data going into the registers, a task which is currently under-performed. An additional problem is that Sweden's quality registers tend to exist in isolation, with little cross-talk between them. Not only does this mean that clinicians may have to enter information on the same patient multiple times to different registers, but also that holistic patterns of care for patients with multiple morbidities (around 1 in 5 of the elderly population) cannot emerge. Every Swedish citizen has a unique social security number, hence record linkage across multiple registers should be used more extensively than is currently the case, once a regulatory framework is in place to ensure data security. It will be essential to ensure that data is published in a format that is understandable and usable by both patients and staff. Audit studies may be needed to confirm this, and staff may need to be offered special training to help them interpret and apply findings from technical reports.

A clearer role for central government is needed to satisfy the need for consistent quality assurance

Greater clarity, particularly of central government's role, is needed to put current reforms on a secure footing and avoid lapses in the quality of health and long-term care for the elderly.

Within the context of Sweden's strongly decentralised governance system, the role of the central government in assuring quality is evolving. In June 2013, for example, Sweden created a new Health and Social Care Inspectorate that will focus on quality assuring health care personnel and health care organisations. Standards for guiding inspections will be signed off centrally and form the basis for assessing local services. Such a shift in governance toward a stronger emphasis on central supervision is entirely reasonable, as long as the contrast with earlier governance styles is openly acknowledged and operational details worked out in a way that involves all those affected. At present, this evolution, whilst consensual, has led to some vagueness and uncertainty around the respective roles and responsibilities of central and local authorities, for example around approving novel services or technologies offered by recent entrants to the care market. The newly created Health and Social Care Inspectorate should offer some additional clarity here.

A number of distinct roles for central authorities can be envisaged which do not impinge on local authorities' freedom to design and deliver services that best meet local needs. These include:

- providing overviews of current practice and/or evidence
- providing tools such as evaluation frameworks, IT platforms, and considering mobile teams to visit areas with special needs
- "levelling-out" resources and workload, particularly for smaller or more remote municipalities
- developing standards or guidance, such as that being developed by the National Board of Health and Welfare.

Central and local government need to identify which responsibilities will be held by each party and which will be shared. Regarding health professionals for example, licensing and approval to work is probably best managed centrally whilst support and appraisal of on-going competence might be best delivered locally. Specifying targets (around the number of hours each health professional should spend on maintaining and updating their competence for example) may help make each role more concrete; *mutual* accountability between central and local government will be key.

This need for quality assurance of at least of some inputs or activities is now recognised at the highest levels of policy making and explains the recent creation of the Health and Social Care Inspectorate. Sweden's path towards centralisation of the quality assurance of health system inputs is part of a trend seen across OECD countries. Centrally determined standards to licence professionals and accredit or inspect services are being developed or already in place in Norway, Denmark and the United Kingdom as well as elsewhere, driven in each case by a political need to demonstrate, through robust and independent means, the quality of key inputs into the health system.

Better support for joint working within and across counties and municipalities is necessary to quality assure pathways of care

At the same time as clarifying roles for central government, new initiatives are needed within local governments' sphere of influence, particularly around supporting better co-ordination and integration of services. Reforms with this objective fall into two broad areas: those intended to support better working within county councils and municipalities, and those intended to support better joint working across both levels of government In particular, there is a need to achieve better co-ordination across all dimensions of Swedish care services: across primary and secondary health care and across somatic and mental health care; across health and long-term care for the elderly; and across medical and public health care.

Of all of these dimensions, the greatest lack of co-ordination exists between health and long-term care for the elderly. These sectors have distinctly different professional frameworks, funding, accountability and organisational cultures in Sweden, as in many other countries. The central government has clearly signalled that in elderly care (as well as other selected domains such as addiction services) these two services must work more closely together. There are a number of mechanisms through which this could be achieved, such as shared patient registers, shared documentation, jointly developed guidelines or joint planning and purchasing agreements. These initiatives should be underpinned by some key principles.

First, there should be strong encouragement for local innovation and development of local solutions; although in some cases it will be obvious that a unified, centrally co-ordinated solution will be more pragmatic, for example around shared documentation. Second, within each joint arrangement, early identification of which roles and responsibilities is key, particularly those that are shared and those that are separate (for example, in conducting surveys of service user experience). Setting goals can help clarify these responsibilities. Mutual accountability between health and long-term care for the elderly services will strengthen any arrangement. Third, all arrangements for shared service provision, mutual support or accountability should fully include new private providers that are now active in health and long-term care for the elderly.

It is also important that innovations are evaluated and learning is shared. At present, this does not always appear to be the case. There are several examples of simple innovations shown to be successful in one area that are not trialled elsewhere, such as having a primary care nurse phone elderly patients within 48 hours of discharge and again after a week to check on progress. SALAR needs to develop better mechanisms to enable contact and exchanges between county councils and municipalities.

Sweden's eventual ambition must be to move beyond quality assessment of single services to the quality assurance of whole pathways of care, from the moment of the emergence of a new health care need to the completion of a treatment plan (which may be on-going over several years), including outcomes and patient experiences. Developing richer information systems, as outlined earlier, as well as clarifying roles and responsibilities will be crucial to this.

Strengthening primary care

As a central, readily accessible, community-based care provider offering a comprehensive range of services by a multidisciplinary complement of skilled staff operating from well-equipped facilities, primary care in Sweden fits the model that many countries aspire to. Today, the foremost challenge for Swedish primary care is to respond to an increasing prevalence of chronic illnesses such as diabetes or heart disease in a way that satisfies public expectations for co-ordinated care and avoids unnecessary use of costly secondary care.

The Swedish health care system is founded upon a well-organised and comprehensive primary care sector, and most patients enter the health care system via this point. Primary care is often arranged as multiple partner establishments staffed by a group of GPs and a wider multidisciplinary team including nurses, physiotherapists, occupational therapists, midwives and psychologists, providing a broad range of clinical care. Many GPs and nurses have special interests in areas such as diabetes or child health. Since the 1970s, Sweden has also encouraged "one-stop shop" clinics where patients can access GPs, specialists and some radiography or laboratory services, thereby extending the range of services available to patients outside hospital.

Sweden performs strongly across several indicators of primary care quality. Childhood immunisation rates are high relative to other countries and the infant mortality rate is among the lowest in the OECD. Sweden's admission rate for asthma is also among the lowest and admission rates for COPD, short and long-term complications of diabetes and amputation rates among diabetic patients are all lower than the OECD average. In the 2011 survey of primary care patients, 90% of people using primary care in Sweden said they were treated with respect and consideration by staff, 78% said they had received sufficient information about their condition, and 78% said they had participated in care and treatment decisions. Not all indicators are as reassuring, however. Less than a quarter of diabetic patients (type I and type II), for example, have adequately controlled blood pressure with a two-fold variation across counties; in older women with osteoporosis who have suffered a fracture, less than 1 in 6 receive appropriate preventive therapy to reduce the risk of another fracture, with a range of 7-22% across counties. These figures suggest that there is still progress to be made in improving primary care quality, secondary prevention and reducing unwarranted variation across localities.

Since the 2010 reforms, over 200 private providers have been established (an increase of over 20%); in Stockholm, about half of all primary care providers are private. Choice and competition in primary care, and the loss of a geographical responsibility for population health, can fragment care and impede partnership between local agencies in providing seamless health and long-term care. This could impact negatively on Sweden’s concurrent policy priority of providing co-ordinated and integrated care, in particular for elderly residents. Any such risk is compounded by the fact that whilst county councils are responsible for GP services, municipalities are responsible for home care and long-term care for the elderly services. The lack of clarity about overall responsibility for care co-ordination, and the role of primary care is an additional obstacle to improving care co-ordination.

The government will need to ensure that:

- there is a clear strategic vision for primary care shared by SALAR, county councils, municipalities and leaders in primary care
- the reforms on choice and competition promote co-ordinated care and avoid fragmentation
- payment and incentive systems foster co-operation, co-ordination and joint working.

Some suggestions on how to achieve these are discussed below.

Enhancing the role of primary care in care co-ordination for elderly citizens

It would seem natural to support the primary care sector to take on responsibility for co-ordinating care more explicitly given its historic de facto adoption of the role, its accessibility and its remit for continuous care.

Older people may receive health care from a variety of sources – county councils, municipalities or private providers – which may not have natural or well-established mechanisms of co-ordinating amongst themselves. In Sweden, the expectation thus far has been that the task of co-ordinating patient care, acting as a navigator across complex pathways of care, and taking responsibility for health care in residential settings, should fall to primary care. There is little formal structure around this role however: sometimes it is undertaken by GPs, at other times or in other settings, primary care nurses or municipality employees may take on the role. There is also variability in the effectiveness with which care co-ordination is achieved. In general, arrangements immediately around the point of hospital discharge are well co-ordinated, but on-going co-ordination once the patient is established in the community is reportedly weak.

There are a number of steps which should be taken to formalise and support adoption of the GP co-ordination role further. Foremost would be to work with the primary care sector and other health care providers to define primary care’s role in co-ordinating care across multiple providers and services. In practical terms this may mean asking primary care teams to draw up and take on responsibility for elderly patient’s care plans upon discharge from hospital or to have a named care co-ordinator for people with complex health care needs. New tasks such as this are likely to require additional resources and training, such as enhancing the number and/or skill base of primary care nurses to allow them to assess the care co-ordination needs of recently discharged elderly patients. Targeted and time-limited financial incentives may be appropriate to support primary care providers to develop this role, rewarding those who can demonstrate they are applying a care protocol for elderly patients recently discharged from hospital, for example.

At the same time, county councils and municipalities should be encouraged to develop integrated models of care, particularly for patients with chronic illnesses, such as COPD, who may need to make intensive use of both community and specialist health services. Mechanisms will be needed to ensure that care co-ordinator roles do not develop in isolation from these innovations, but that the two strands of initiative advance compatibly and synergistically at the local level. A specialist nurse managing an integrated COPD service, for example, will need a close working relationship with primary care nurses co-ordinating the care of complex patients in a particular locality. In particular, special attention should be paid to ensure that there are sufficient checks and safeguards in place to counter risks of fragmentation given the incentives for providers to compete. Regular surveys of patient experience and satisfaction would be an appropriate tool in this regard.

Using information and standards to improve care quality and co-ordination

The lack of data on activities and outcomes in primary care hampers several policy priorities such as benchmarking providers, giving patients sufficient information to exercise choice and demonstrating effective care co-ordination.

Compared to the hospital sector, primary care in Sweden is characterised by a lack of quality indicators or other measures which allow an assessment of the patterns of care and outcomes. The quality registers for diabetes and dementia, for example, contain some primary care data, but coverage is incomplete. Furthermore, the culture of using data for quality improvement is less deeply embedded in Swedish primary care compared to secondary care. This is partly due to the difficulty in capturing and quantifying many of the activities which take place in the sector but also relates to a relative lack of guidelines and standards to define what primary care in Sweden should look like. The government is moving to address the issue but given the lack of quality standards, disparate IT and classification systems, devolved administrations and the established culture of having disease-focussed rather than patient-centered quality registers, the speed of implementation is likely to be slow.

Sweden should look toward developing a set of quality national standards and supporting data collection for primary care as a first step. Although setting out national standards may herald a departure from Sweden's preferred governance style, it is consistent with the direction of travel taken by the National Board in developing nationally applicable care standards. Several examples of primary care quality standards are available internationally (such as those developed by Joint Commission International) and could form the basis for Swedish standards developed jointly by central and local government, patient and professional groups.

Applied locally by councils and municipalities on a national basis, these standards would ensure consistency in the quality assurance of primary care and form a rich source of quality related information. Additional means to deepen the information infrastructure would be to extend the amount of primary care related data collected through Sweden's various quality registers and standardising, where possible, the IT and data classification systems used in primary care to code activity and outcomes.

Equipping primary care professionals with the right skills

Prevention, both primary and secondary, is a key role for primary care, critical to reducing the burden of chronic disease and multiple morbidities. Sweden could be doing better here.

There is evidence from national quality registers that prevention and early diagnosis of chronic health conditions could be improved, as well as secondary prevention of complications once the conditions are established. Less than half of type I diabetics, for example, have their blood pressure adequately controlled, with an almost three-fold variation (from 26% to 68%) across counties. The role of primary care in mental health care also needs improvement, including early diagnosis of dementia, physical health care for people with mental health problems, access to psychological therapies and the interface with specialist mental health services. GPs do not seem to be doing enough to improve the physical health of people with mental health issues, for example. Likewise, when people are referred to specialist services, the link with primary care is not maintained. A more proactive role for primary care in prevention, management of chronic disease, mental illness and multi-morbidities, will improve longer-term health outcomes and reduce use of specialist care and health care costs. Sweden has an excellent primary care foundation from which more proactive management of these areas can emerge. Its primary care workforce is highly skilled, multidisciplinary and well resourced.

To meet these challenges, central government should identify the training needs of primary care doctors and nurses around prevention and multiple morbidities and ensure that this workforce is appropriately skilled to deliver co-ordinated care to an ageing population with increasingly complex care needs. The government should also ensure that the supply of primary care staff numbers will be adequate to address the health care needs of the Swedish population over the next decade, and that investment in primary care is modelled on projected demands on primary care, including any anticipated reallocation of tasks away from the hospital sector.

Better assurance for quality in long-term care

Whilst Sweden has comprehensive long-term care (LTC) for the elderly, the lack of information of quality and outcomes means that it is difficult to demonstrate its value, while co-ordination across health and social care in LTC remains a challenge.

A well-established feature of Swedish public life is the expectation that the public sector be primarily responsible for organising and providing care when elderly citizens are no longer able to live independently. With

73.4 long-term care beds per 1 000 people over 65 years, Sweden's density of long-term care beds is second highest in the OECD after Luxembourg, well above the OECD average of 49.1. Similarly, Sweden has the highest number of LTC workers in the OECD. More recently, there has been an emphasis on keeping older citizens in their home environment for as long as possible. Sweden demonstrated the largest fall in the supply of LTC beds across OECD countries, averaging an annual reduction of 1.2% for beds in institutions and of 4.0% for long-term care beds in hospitals between 2000 and 2011. The share of home care recipients increased markedly over time, from just over half in 2000 to seven out of ten recipients in 2011.

The combination of comprehensive coverage, few out-of-pocket expenses at the point of service, a wide use of assistive technologies, and a renewed emphasis on supporting people to remain at home as long as possible means that Sweden is one of the highest spenders on long-term care in the OECD. Sweden spends 3.6% of GDP on LTC, compared to an OECD average of 1.7% and second only to the Netherlands. Projections suggest continued growth in spending. While there seems to be widespread willingness to pay high taxes for generous care for the elderly, for such a level of public spending there needs to be high public accountability and transparency regarding efficiency and quality. Currently, however, it is very difficult to demonstrate either of these for long-term care in Sweden.

As with primary care, the governance structure around long-term care is split, with municipalities being responsible for institutional care and nursing care in private homes, and county councils being responsible for the delivery and financing of medical care. There are few built-in incentives for co-ordination across these governance levels or across the health and social care components of long-term care services. Whilst central government has set out a holistic vision for care of the elderly this has not successfully translated to local implementation, as evidenced by a frequent absence of joint care planning, joint purchasing or bundled payments, and persistent high levels of unnecessary hospitalisation for the elderly. For example, at 260 admissions per 100 000 people aged over 80, avoidable hospital admissions for uncontrolled diabetes in Sweden's elderly population are the sixth highest in the OECD. While some excellent initiatives for closer joint working have been developed in individual localities such as Lidköping, Gävle and Jönköping, they have met with limited interest more widely – Sweden's tradition of strong local government means that successful innovations in one area are not always rolled out more broadly.

Sweden is internationally regarded as a model for long-term care, but relatively little is known about quality

The absence of quality indicators in elderly care is the foremost problem facing those who manage and those who use long-term care. The lack of measures means that it is difficult for policy makers to identify areas requiring improvement and, furthermore, there is no connection between service quality and the price paid for them. From the recipients' perspective, it may be difficult to choose among the different providers. Competition across providers, where it exists, is therefore not driven by quality but practical considerations such as location or the type of services offered.

Whilst the absence of indicators of long-term care quality is a problem shared by many OECD countries, Sweden is in a good position to spearhead international efforts to develop quality measurement in this sector, given its extensive experience with quality registers in other areas. A long-term care information system will need to do two things: give providers information on cost and quality and support users, especially the least able, to choose the right services for them. Sweden has already started to meet this challenge in piloting medication safety and avoidable hospital admissions indicators and joint work between national authorities, municipalities, service providers and academics to validate these indicators and identify additional ones – such as rates of pressure ulcers, polypharmacy, depression, or falls – should continue.

As in primary care, there is also scope to make better use of information that already exists, in particular through standardising documentation systems across long-term care settings and strengthening linkages between relevant quality registries to get a richer picture of elderly's care needs and experiences of care. Linking pre-existing data sources on dementia, medication and falls for example would open up new avenues to explore deficiencies in the quality of care for a particularly vulnerable group of patients. Assuming a richer information system can be established, Sweden should look to extend the set of quality indicators relating to long-term care included in SALAR's Open Comparison publication. Qualitative work will also be needed to assess the extent to which long-term care users make informed choices of providers based on this information.

Quality standards for long-term care should be established

Whilst competition between plural providers can be a powerful instrument for change in a decentralised system of governance, there is still a need to agree minimum standards of care quality on a national basis to avert the risk of major market failures or instances of suboptimal care. Sweden should move, then, toward developing minimum quality standards around long-term care, focussing on standardising the assessment and care planning of individual patients, accreditation standards for institutions and services providing long-term care, and training and qualifications for staff, particularly home care workers. This shift toward a more managed approach to quality assurance in the long-term care sector need not conflict with the market-driven solutions used thus far, but will instead underpin them. As noted earlier, it will be essential to ensure that initiatives fully include alternative providers and recent entrants to the care market.

Development of quality standards should be a joint effort undertaken by national authorities, local governments and providers. In some instances an incremental approach would be appropriate, particularly where it is clear that a longer time frame will be needed to reach desirable minimum quality standards. This is likely to be the case, for example, regarding minimum staff competencies. Here, a sensible approach would be to monitor the participation of municipalities in the *Omvårdnadslyftet* project to upgrade skills of institutional care workers, gradually expanding these efforts to home care workers, and, in the medium to long-term, considering ways to agree with municipalities on minimum training/qualification standards for care workers. To support attainment of the standards, a range of protocols and guidelines could be envisaged. For example, interRAI's Clinical Assessment Protocols, used in a number of OECD countries, have been developed by a multinational group of academics and clinicians to help long-term care workers identify the need for care plans and address risk factors in elderly individuals. In France, national agencies dealing with care have developed good practice guidelines, while in Japan, providers themselves develop their own set of guidelines.

Co-ordination across services and providers could also be improved

There are few incentives for providers in Sweden to co-ordinate care and ensure seamless care transitions, an important dimension of efficiency and of patient experience. Co-ordination is particularly important in the domain of long-term care: this group of service users may have functional and cognitive limitations and are dependent on help from multiple caregivers. From an organisational point of view, however, it is not always clear where the responsibilities for medical treatment end and where nursing and social care for the elderly begins, whether in home or institutional settings.

The lack of a clear definition and explicit accountability rules can lead to attempts by county councils and municipalities to transfer responsibilities and costs to one another, resulting in frail dependent elderly individuals not receiving the right combination of medical, nursing and other support they would need to improve the quality of life. A related issue is that the flow of information from different settings barely exists in Sweden, between hospitals and nursing homes, or between GPs and home care services. Laws on patient privacy restrict a shared record system and municipalities often do not have the necessary equipment and capacity to keep comprehensive patient-level records and to track patients across different care settings. Hence, like many countries, even though a data collection infrastructure in the health sector exists, Sweden remains a long way from having a cohesive information system for elderly care.

There are, however, several steps which Sweden could take to encourage care co-ordination in the provision of long-term care. Substantial co-ordination yields will flow from the development of quality standards, guidelines and information systems that cover all relevant providers as outlined above. Additional work will also be needed to develop the legal framework and practical systems to facilitate exchange of records across providers. At the level of service delivery, local governments should be encouraged to experiment with innovative forms of integration, including joint planning and purchasing models and developing new roles such as jointly accountable care co-ordinators or multidisciplinary teams tasked with identifying and working with people with complex needs. Examples of such innovations can be found in France (the Service Intégré de Soins à Domicile), the United States (Care Transition Coaching and social health maintenance organisations) and Canada (the system for Integrated Care for Older People in Quebec). It will be essential to ensure that innovations are evaluated and learning shared. Municipalities are likely to require support for this, such as provision of additional resources to undertake evaluations or regular compilation of innovations and impact evaluations taking place at local level to facilitate mutual learning.

Improving care after hip fracture and stroke

The degree to which a health system routinely provides high-quality health care after a stroke or hip fracture directly reflects its capacity to provide a complex and tailored array of health and long-term care services in the face of sudden and unexpected disability. Both stroke and hip fracture have relatively high incidence rates within Sweden, each affecting around 20 to 30 thousand individuals annually. Both events are associated with significant loss of independence and function – most notably for those who were living independently before the acute event. Likewise, – for each there exists a relatively extensive evidence base of effective interventions, such as prompt medical treatment and personalised rehabilitation starting as soon as the acute event has settled. This can reduce functional loss if offered early enough, intensively enough and for long enough. For each of these reasons, then, the pathways of care following stroke and hip fracture should be exemplars of the quality of care for patients within the Swedish health care system.

Quality of acute hospital-based care after hip fracture and stroke is high, in part driven by the Quality Registers which monitor patterns of care for these patient groups. For example, surgery on hip fractures is almost always performed within 24hrs of admission and patient groups for stroke care report that they are happy with the emergency response or care provided in hospitals. Yet, while the acute phase of care within hospitals appears generally good, patients' experience of on-going care once discharged is less promising. More than a third of patients with a stroke report, for example, that their rehabilitation needs have not been met twelve months after the acute event. Although this may reflect a degree of unrealistic expectation, it nevertheless signals the extent of dissatisfaction with services as currently provided. An equivalent measure for hip fracture patients is not available, the absence of which signals a quality issue in its own right.

Most reasons for this poorer experience of on-going care after hospitalisation relate to a lack of clarity around the quality standards to which community-based care should aspire to, inadequate arrangements for quality monitoring and insufficient incentives and mechanisms to encourage co-ordination across the different care services needed in the community. The steps already outlined that Sweden needs to take to address these challenges will bring about direct improvements to the quality of care for these two clinical areas. There are, however, some additional observations specific to stroke or hip fracture that are relevant.

The unequal quality architecture around the two clinical areas signals an unevenness of approach

Despite stroke and hip fracture being broadly comparable in terms of incidence rates, the breadth of care needs that they trigger, relatively advanced evidence bases setting out optimal care and marked regional variation within Sweden regarding process and outcome measures, the quality architecture around the two conditions is rather unequal. Stroke care, for example, benefits from national clinical guidelines and a national performance report from the National Board of Health and Welfare, bringing together diverse data sources and making strategic recommendations for future service development. There are no equivalent guidelines or national performance report for care after hip fracture. The contents of the two quality registers also differ, that for stroke including patient satisfaction measures as noted above, which are not included in the hip fracture quality register, for example.

Reasons for these differences lie in the distinct historical trajectories that quality improvement initiatives for each area, largely led by clinical professionals working in the field, have taken. While this bottom-up approach has some advantages, including freedom to innovate and develop initiatives that best meet specific needs, it is also an illustration of the inconsistent approach taken to quality assessment, assurance and improvement in Sweden, which could now benefit from greater standardisation at a national level. The need to take a standard approach to quality in clinical domains such as stroke and hip fracture is particularly important because the pathway of care for these conditions crosses several boundaries (between primary and secondary health care and between health and long-term care for the elderly in particular) and so is central to Sweden's ambition to achieve better integrated care.

Formulating a more consistent quality approach to distinct clinical areas will require the Swedish authorities, in association with professional and patient groups, to set out the quality architecture it wishes to see in place for each area. This may include minimum quality standards, joint health and long-term care for the elderly guidelines, quality registers that include patient experiences, regular national strategic reviews and so on. Special attention should be paid to assuring quality for the frailest elderly and ensuring that any risk of fragmented care engendered by choice and competition reforms is monitored and, if necessary, minimised.

More needs to be achieved around secondary prevention, especially through primary care

The quality of secondary prevention, which reduces the risk of a second stroke or fracture, is a particular concern in Sweden. Less than one in six patients nationwide are on preventive treatment six to twelve months after a fracture (with treatment rates across counties varying from 7 to 22%), far short of the 60-70% rate that most scientific studies conclude is necessary, taking into account those with and without osteoporosis. Regarding stroke care, independent scientific studies have shown that although nearly all patients leave the acute setting on appropriate secondary preventive medication such as antithrombotic, antihypertensive and lipid lowering agents, continued medication use falls to 50% after a year. Furthermore, a third of patients have had no contact with a physician in the first three months after discharge.

Hence, better management of on-going risk must be a particular priority for Sweden. In theory, secondary prevention can be managed either through hospital out-patient clinics or through primary care, but given the trend to shift care outside the hospital setting and the need to situate secondary preventive efforts in the context of a patient's complete medical record and medication history, it seems more sensible that the task should be taken up by primary care. This area is one therefore where the need for clarifying the roles and responsibilities of primary care in the co-ordination of care becomes obvious.

Having clarified responsibilities, more effective secondary prevention could be achieved by setting out standards or guidelines for secondary prevention after cardiovascular events and fragility fractures. Guidelines should also be published in a format understandable to patients and patient-oriented decision aids (setting out risks and benefits visually, for example) should also be considered. Adequate monitoring of secondary prevention should be ensured, either by including additional data points within the relevant quality registers or ensuring appropriate data linkage with other sources such as prescribing databases. Targeted and time-limited financial incentives may be appropriate to support implementation.

Policy recommendations for improving the quality of health care in Sweden

Given Sweden's aim to improve health and long-term care for older citizens, its foremost challenge is to ensure that the values of local governance, choice and competition are balanced against the needs to assure quality in a consistent manner and to avoid fragmentation of care. In particular, Sweden should

1. Improve its general quality of care policies:

- Develop richer and more effective information systems, for example by:
  - improving the information infrastructure underpinning primary and long-term care services, by aligning IT inter-compatibility, classification systems and establishing minimum quality standards for IT platforms
  - validating new quality indicators in the primary care and long-term care services, such as rates of falls, pressure ulcers or polypharmacy in the elderly
  - better using existing quality measures through improvements in the IT infrastructure beneath quality registers and care records, ensuring where possible that underlying data-sources are identically structured
  - exploring possibilities to link data from different sources to capture a more comprehensive picture of the patterns of care and outcomes for individuals
  - extending the systematic measurement of patient experiences to include long-term services, with a particular focus on integration and continuity.
- Define a clearer role for central government whilst still allowing freedom to tailor services and improvement activities to the local context, for example by:
  - providing county councils and municipalities with evaluation frameworks, overviews of evidence, current practice or performance
  - developing mobile teams to visit areas with special needs
  - publishing minimum quality standards around inputs (such as health care professionals and technologies), processes and outcomes
  - considering introduction of a more formal process for assessing individual professionals' performance and assuring the quality of health care organisations.
- Support better joint working within and across local governments by:
  - encouraging shared patient registers or documentation, jointly developed guidelines or joint purchasing and planning arrangements to integrate local health and long-term care services

Policy recommendations for improving the quality of health care in Sweden *(cont.)*

  - encouraging continued innovation in how county councils and municipalities design and deliver services, for example by creating new professional roles to meet the need for better care co-ordination
  - ensuring that innovations are evaluated and the learning effectively shared across county councils and municipalities on a county-by-county basis or nationally.

2. Improve the quality of primary care:

- define the role that primary care is expected to play in caring for an ageing and increasingly multi-morbid population and in co-ordinating their care across multiple providers
- adequately invest in primary care staff numbers and training to ensure that they have the capacity and skills to fulfil this role
- encourage and incentivise county councils and municipalities to work in partnership to foster integrated models of care, embedding a central oversight role for primary care within each arrangement
- define a set of core quality standards for primary care that can be used to consistently and transparently monitor, assure and improve aspects of the service, around the identification and management of chronic illnesses
- study the effects of recent choice and competition reforms to ensure that they do not fragment services for patients with complex needs
- equip the primary care workforce to play a more proactive role in primary and secondary prevention of chronic disease and in the management of mental illness, through additional training or clinical guidelines for example
- standardise the information infrastructure in primary care to support improvements in the measurability of quality in primary care on a consistent basis.

3. Encourage quality measurement and improvement in the long-term care sector:

- work with municipalities and counties to develop a vision for quality assurance of long-term care services, including minimum quality standards, an accountability framework and a shared framework for monitoring outcomes in long-term care
- strengthen the measurement of quality in long-term care by:
  - working with municipalities to develop new quality indicators based on outcomes as far as possible, such as rates of pressure ulcers or falls, and developing specific quality registries covering long-term care users

Policy recommendations for improving the quality of health care in Sweden *(cont.)*

  - standardising records in long-term care settings and strengthening linkages across municipalities, counties, hospitals, GPs and other care providers
  - encouraging comparisons of performance across providers and decentralised levels of government through open comparison.

- consider ways that choice and tailoring of care can be harmonised with the advantages of greater care standardisation, for example by:
  - engaging providers and municipalities in efforts to introduce greater use of quality standards, protocols and guidelines
  - expanding efforts to assure minimum long-term care workforce competences
  - moving to a system of regular periodic assessment of provider performance or developing indicators systems which trigger inspections when concerns arise.
- encourage co-ordination across health and long-term care for the elderly by:
  - working on a national system to facilitate exchange of records across health and care settings
  - developing joint social and health care guidelines
  - encouraging innovative forms of integration, such as joint care co-ordinators, multidisciplinary teams and joint health and care planning and purchasing models.
- ensure continuous capacity development and learning across local governments by compiling evaluations of innovative initiatives.

4. Address deficiencies in care after stroke or hip fracture

- develop, as for primary care and long-term care, minimum quality standards for these conditions
- develop protocols or guidelines, monitoring and accountability frameworks for integrated care in these conditions
- align more closely the depth and breadth of the quality architecture around stroke and hip fracture, ensuring that the quality registers for each include patient reported outcomes for example
- strengthen secondary prevention efforts by clarifying responsibilities for prescribing and monitoring secondary prevention, setting standards and developing guidelines oriented to both patients and professionals.

Chapter 1

Quality of health care in Sweden

This chapter summarises the many policies and activities that are in place in Sweden to assure and improve quality of care. After describing the quality governance structure and the roles of central government, its agencies, county-councils/regions and municipalities, the chapter focuses on the assurance of the quality of professionals, pharmaceuticals and devices and health care organisations. The development and use of national guidelines and the Swedish data infrastructure is described, including the important role of registries and systematic measurement of patient experiences. Specific attention is given to measurement and improvement activities related to patient safety.

The chapter concludes that Sweden has a well-developed model for quality management. Challenges remain, however, in aligning the various quality assurance and quality improvement functions in the Swedish health care system for individual professionals, health care organisations and local health care delivery systems, particularly in relation to closer working between health care and social care. Broadening measurement activities of registries and patient experiences to social care together with strengthening focus on data on quality of care in the e-health strategy are recommended.

In short, the chapter highlights how emphasis should shift from quality assessment of clinical care towards quality assurance and quality improvement of integrated service delivery.

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

1.1. Introduction

Sweden has a long tradition of initiating activities and strategies to assure and improve the quality of its health care. Experience with monitoring clinical quality through a series of clinical registries stretches over 30 years; over the past decade, systematic measurement of patient experiences through national surveys has been added. Sweden is also a leading country in terms of addressing patient safety concerns.

Embedded in a system that puts dignity, solidarity and cost-effectiveness as core values, Sweden's challenges is to balance these national quality strategies against a decentralised model of health care delivery where responsibility for ensuring access to high quality health care and social services lies with the county councils/regions and municipalities.

This chapter takes stock of the existing quality of care policies and assesses their characteristics in comparison with similar strategies applied in other OECD countries. The description is structured according to a framework that is detailed in Table 1.1 that distinguishes health system design, health system inputs, health system standards and monitoring and health system improvement. After providing some general context information, the chapter addresses:

- the *legislative framework and governance* for quality of care in Sweden
- the quality assurance of *health care inputs* including health care professionals, technologies and health care organisations
- policies related to *standards and guidelines* for quality of care
- policies for *measuring* quality of care and the related information infrastructure and public reporting
- policies aimed at *health system improvement* such as recent patient safety initiatives.

A short description of the Swedish health care system is provided in Box 1.1. For more detailed information on the Swedish health care system, the European Observatory's "Health Systems in Transition" report on Sweden offers a useful source of information (Anell et al., 2012).

Table 1.1. A typology of health care policies that influence health care quality

Policy	Examples
Health system design	Accountability of actors, allocation of responsibilities, legislation
Health system input (professionals, organisations, technologies)	Professional licensing, accreditation of health care organisations, quality assurance of drugs and medical devices
Health system monitoring and standardisation of practice	Measurement of quality of care, national standards and guidelines, national audit
Improvement (national programmes, hospital programmes and incentives)	National programmes on quality and safety, pay for performance in hospital care, examples of improvement programmes within institutions

Box 1.1. Key characteristics of the Swedish health care system

In Sweden, the state is responsible for overall health policy, while the funding and provision of services lies largely with the county councils and regions. The municipalities are responsible for the care of older and disabled people. The majority of primary care centres and almost all hospitals are owned by the county councils. Health care expenditure is mainly tax funded (80%) and is equivalent to 9.9% of gross domestic product (2009). Only about 4% of the population has voluntary health insurance (VHI). User charges fund about 17% of health expenditure and are levied on visits to professionals, hospitalisation and medicines. The number of acute care hospital beds is below the European Union average and Sweden allocates more human resources to the health sector than most OECD countries. In the past, shortcomings of Swedish health care included long waiting times for diagnosis and treatment and, more recently, divergence in quality of care between regions and socio-economic groups. Addressing long waiting times remains a key policy objective along with improving access to providers. Recent principal health reforms over the past decade relate to: concentrating hospital services; regionalising health care services, including mergers; improving co-ordinated care; increasing choice, competition and privatisation in primary care; privatisation and competition in the pharmacy sector; changing co-payments; and increasing attention to public comparison of quality and efficiency indicators, the value of investments in health care and responsiveness to patients' needs. Reforms are often introduced on the local level, thus the pattern of reform varies across local government, although mimicking behaviour usually occurs.

Source: Anell, A., A.H. Glengard and S. Merkur (2012), "Sweden: Health Systems in Transition", *Health System Review*, Vol. 14, No. 5, European Observatory of Health Systems and Policies.

1.2. Context

Sweden performs well on the majority of quality indicators, also compared with other Nordic countries

Sweden's life expectancy at birth of 81.9 years puts it in the top quartile of OECD countries, and above Norway (81.4), Finland (80.6) and Denmark (79.9). With an increase in life expectancy with 7.1 years over the period 1970-2011 Sweden has experienced more than half a century of increased health coupled with increased wealth.

Five-year relative survival estimates for breast, cervical and colon cancer are for Sweden amongst the highest in the OECD. Breast cancer five-year survival estimate over the period 2006-11 is 86.3% (OECD average 84.2%, United States 89.3%, Norway 86.1%, Finland 85.9% and Denmark 82%). Cervical cancer five-year relative survival estimate over the period 2006-11 is 68.4% (OECD average 66%, Norway 71.4%, Korea 76.8%, Finland 65.1% and Denmark 66.4%). The five-year relative survival estimate for colorectal cancer over the period 2006-11 is 63.1% (OECD average 61.3%, Japan 68%, Norway 62.9%, Finland 63.8% and Denmark 55.5%). The recent reform in 2011 to institutionalise regional cancer centers will most likely only enhance this performance.

In-hospital case fatality rates within 30 days after admission for acute myocardial infarction (AMI) are amongst the lowest in the OECD, with a reported age-sex standardised rate of 4.5 deaths per 100 patients (OECD 7.9; Denmark 3.0, Norway 4.5, Finland 7.0). In-hospital case fatality rates within 30 days after admission for ischemic stroke are also relatively low at 6.4 deaths per 100 patients (OECD 8.5; Finland 5.4, Norway 5.3, Denmark 4.1). A more in depth analyses of the situation with stroke care in Sweden is provided in Chapter 4.

Admission rates for chronic conditions which are deemed to be manageable in primary care are relatively low in Sweden (asthma 22.2 admissions per 100 000 population compared to OECD average 45.8; Denmark 36.3, Norway 28.1, Finland 67.8; COPD 168.8 admissions per 100 000 population compared to OECD average 203, Finland 143.4, Norway 210.6, Denmark 291.8). Whether this can be considered indicative for the functioning of primary care in Sweden is analysed in more detail in Chapter 2.

Despite these positive results on performance indicators, publications of the Nordic Council comparing Sweden with the other Nordic Countries in more detail as well as internal Swedish reports such as the *Quality and Efficiency in Swedish Health Care* report demonstrate that behind these figures there are also weaker areas as well as geographical differences between the counties and regions.

Such differences form an important input for the quality strategies in Sweden, where local responsibility for health care delivery is coupled with a strongly developed system of accountability based on performance data. The focus of recent reforms focusing on the introduction of private providers in health care, patient choice and further decentralisation of responsibilities to the municipality level have enforced the need for data on performance of health care professionals, health care providers and local health care delivery systems. Transparency and accountability are key terms in the present debates on strategies for quality assurance and quality improvement.

1.3. Health system design

Supporting and monitoring nationally and acting locally

With primary responsibility for the delivery of good health care at the level of the county councils/regions and municipalities, the Swedish governance model is a mix of a decentralised organisation of health care services and centralised setting of standards, supervision and compilation of performance information on county/region based services. Furthermore, reforms since the 1990s have devolved responsibilities of health care providers (particularly care for the elderly) even further from county level to municipal level. This has created challenges, not only to assure municipalities' competence to deliver these services, but also to ensure adequate co-ordination between social care and nursing home care services on the one hand and primary care and hospital services on the other.

In terms of hospital care, reforms over recent years have focussed on concentrating services into fewer centres at the same time as shifting care to ambulatory care settings. Overall, a higher aggregate level for organising services has been introduced, resulting in seven university hospitals in six medical care regions and approximately 70 county council operated hospitals. A small number of private hospitals also provide specialist care.

Sweden has invested in robust quality registries to capture clinical performance over several decades. Recent additions to the data infrastructure include systematic collection of patient experiences to capture the patient centeredness of care (since 2001), data on waiting times and equity (in response to the waiting time guarantee in 2005) and data to monitor implementation of patient safety legislation enacted in 2010. The Swedish governance model for quality reflects the overall value put on performance data and leaves a substantial amount of freedom for county councils/regions and municipalities to make their own arrangements. This is reflected in the legal framework on quality and the profile and activities of various institutes at national level.

Separate laws on patient safety and patient rights are embedded in a broader legislative framework underpinning quality of care

There are several laws and regulations that in various ways address quality of care and its components (that is, effective, safe and patient-centered care). The *Hälso- och sjukvårdslagen*, or Health and Medical Services Act (listed as 1982:763 in the Swedish Code of Statutes) the *Patientsäkerhetslagen,* or patient safety act (listed as 2010:659) and *Patientsäkerhetsförordningen,* or patient safety ordinance (listed as 2010:1369) being the principal ones. This legislative framework is based primarily on the obligation of the health care sector to provide safe care of good quality, addressing both the responsibilities of organisations providing health care services as well as the individual responsibilities of health care professionals. Both organisations and professionals have to meet minimum qualification criteria, take on responsibility for quality and comply with supervisory mechanisms, mainly via the National Board of Health and Welfare.

The Health and Medical Services Act stipulates that medical care shall be provided with due respect for equality and privacy and that priority shall be given to those who are in the greatest need of health and medical care. Additional requirements are that care should be of high quality with a good standard of hygiene and safety, be easily accessible, promote good contact between the patient and health care personnel and satisfy the patient's need for continuity and safety in health care. Health care and treatment should, where possible, be formulated and carried out in consultation with the patient. The law also stipulates that patients should be provided with individually adapted information and health care services and specifies the conditions under which a county council is obliged to offer patients a second opinion.

Patient safety is defined in the 2010 legislation as protection against care related injuries (including any suffering, physical injury, psychological harm or death) that could have been avoided if adequate measures had been taken during the patient's contact with health care providers. Severe care-related injury is defined as care-related injury which is permanent and has resulted in the patient having a significant increase in their need for care or their death. In line with earlier legislation, the Act stipulates that health care should be effective (based on evidence), safe and patient-centered. Although separate laws on quality or patient rights do not exist, the related principles are deeply embedded in the prevailing legislation. However, given the political emphasis on patient rights and patient involvement in health care, especially related to care for the elderly, discussions are on-going on new legislation on patient rights.

A series of quality assurance and quality improvement functions is fulfilled by various institutions at the national level

As mentioned before, the Health and Medical services Act of 1982 assigns the 17 county councils, four regions and 290 municipalities prime responsibility for organising health care, leaving them considerable freedom. The state, through the Ministry of Health and Social Affairs, is responsible for overall health care policy.

A series of government agencies are directly involved in the area of health, medical care and public health: the National Board of Health and Welfare (*Socialstyrelsen*), the Swedish Council on Technology Assessment in Health Care (*Statens Beredning för Medicinsk Utvärdering*, SBU), the Swedish Agency for Health Care Services Analysis, the National Institute for Public Health, the Swedish Social Insurance Agency, the HSAN (*Hälso-och Sjukvårdens Ansvarsnämnd*, or Medical Responsibility Board which decides disciplinary measures in the event of complaints or possible malpractice) and the Medical Products Agency (*Läkemedelsverke,* or MPA which regulates pharmaceutical products and devices). Two other national bodies acting as stakeholders in the debates on quality of care are SALAR (*Sveriges Kommuner och Landsting*) and the National Audit Office (*Riksrevisionen*). In June 2013, the Health and Social Care Inspectorate was created to take over the supervisory activities of the National Board of Health and Welfare.

SALAR represents the county councils/regions and the municipalities, formed in 2007. The organisation promotes and aims to strengthen local self-government. As well as providing local authorities with practical support and advice, it represents one of the largest employers in Sweden and negotiates terms of employment for local government officials.

The National Audit Office is part of the formal regulatory framework applied around the Swedish Government. The agency has recently shown increasing interest in auditing health care and is planning to study the compliance of the health care system with the criteria set out in the Swedish Health and Medical Services Act. The focus of this work will be, amongst others, dental care, pre-hospital care including the ambulance service, and quality registries.

The National Board on Health and Welfare has 1 500 staff engaged in a wide range of activities in the areas of social services, health care services, environmental health, communicable disease prevention and epidemiology. The Board develops standards and guidelines, monitors compliance and publishes national reports on performance related to these guidelines, drawing on information within the several data registries and official statistics it manages. In addition, all health personnel and health care providers come under the supervision of the National Board, particularly with respect to ensuring the safety of health care.

Further alignment of quality assurance and quality improvement of national agencies and local/regional health care delivery systems seems advisable

As in other countries with a developed governance model for quality assessment, assurance and improvement, it is clear from the above description that several institutes are in place in Sweden to execute the various functions of standard setting, evaluation of compliance and remedial actions where performance is found to be deficient. Support for quality improvement initiatives on a local level is also in place. Although there is not an ideal governance model for assigning these various functions related to quality of care across different institutions, there is a tendency across OECD countries to separate standard setting, control, disciplinary action and quality improvement/knowledge exchange functions, according to the classical tripartite division of legislation, policing and judging.

Given the fact that Sweden has so far not developed and institutionalised self-regulatory mechanisms such as obligatory re-certification of professionals or accreditation of health care institutes (see Section 1.4), there was, until the creation of the Health and Social Care Inspectorate in June 2013, a void in the inspectorate function. In many OECD countries there are combinations of self-regulatory quality assurance mechanisms to assure the performance of individual practitioners and/or accreditation of health care organisations in combination with an inspectorate role often executed by government agencies. In Sweden, creation of the new Inspectorate should help clarify and strengthen these functions.

Likewise it might be of interest to assess the alignment of the eight government agencies and their mutual roles and responsibilities towards assuring the quality of health care and health system development and performance. For such an assessment it is advisable to discern the functions of quality assurance (standard setting, control and remedial actions) and quality improvement (guidelines, monitoring, feedback and re-evaluation) and make a distinction between activities focused on individual health care professionals, health care services (hospitals, nursing homes) and local health care delivery systems.

An additional focus for such an assessment and alignment of national bodies should be on the differences between social care and health care, including the differences in the legislative basis for quality assurance and quality improvement in these two complementary sectors. Quality assessment, assurance and improvement in health care and social care should act in synergy on the local level and national policies should support this.

1.4. Assuring the quality of inputs to the Swedish health care system

Licensing of health care professionals is well developed but continuous medical education is not mandatory

The policies for licensing health care professionals in Sweden differ depending on in which country the health care professional has been trained. Health care professionals trained in Sweden are licensed according to the 2010 patient safety act and patient safety ordinance discussed in Section 1.3. A health care professional with the relevant diploma from a Swedish university or university college is entitled to be licensed. For some professions the diploma has to be supplemented with a certificate of completion of a specific internship/practice experience.[1] Health care professionals trained within the European Economic Area are licensed according to the directive 2005/36/EC.[2]

Health care professionals trained in a country outside the European Economic Area are licensed according to the same statutes. Their training is compared to the corresponding Swedish training and, if found equivalent, the professional must prove his or her competence of the Swedish language and pass tests on clinical knowledge and skills, Swedish society and legislation. Precise requirements differ depending on the profession.[3]

There is no policy of re-certification, hence there is no formal mechanism to assess on a regular basis individual professional performance and whether an individual is still fit to practice as for example exists in the United Kingdom and the Netherlands. No date of expiration is attached to the license to practice and a license is valid on a life long-term unless legal proceedings lead to revocation. Health care professionals are supervised by the National Board of Health and Welfare. Upon an application from the National Board of Health and Welfare, the Medical Responsibility Board (HSAN) judges if certain circumstances, such as misconduct, criminal offence, violation or illness, should lead to probation or revocation of the license.[4]

Sweden does not have an accreditation system for health care organisations

At present, there are no comprehensive accreditation programmes for hospitals or other health care services. However, the topic is currently under discussion. The National Accreditation Authority (*Styrelsen för ackreditering och teknisk kontroll*, SWEDAC) accredits medical laboratories that comply with requirements in relevant European Union standards (referred to as EN ISO standards). The system is voluntary and coverage is currently around 95% for clinical chemistry laboratories, 95% for clinical microbiology and 75% for transfusion medicine.

One of the 21 county councils/regions in Sweden has certified their health care services according to EN-ISO 9001:2008, which specifies how an organisation should demonstrate its ability to consistently provide a product that meets customer and applicable statutory and regulatory requirements. A few other county councils/regions have certified some of their services according to this standard. Of note, Sweden took the initiative to develop a European quality management systems standard for health care services (known as EN 15224) available since September 2012. Certification of health care services according to EN ISO 14001, which focuses on controlling environmental impact, is common.

There is a good basis for quality assurance of medical devices and pharmaceuticals

The MPA (Medical Products Agency) is the Swedish national authority responsible for the regulation and surveillance of the development, manufacture and sale of drugs and other medical products. They also assess whether products are used in a rational and cost-effective way. The legislation in Sweden is based on two EU Directives, Council Directive 93/42/EEC concerning medical devices and 2001/83/EC Medical Products for human use. Various surveillance activities are in place and there is a link with patient safety initiatives. In principle the developed information infrastructure in Sweden with various registries as well as the tradition of technology assessment studies (SBU) constitutes a good basis for monitoring the quality of the use of medical devices and pharmaceuticals.[5]

1.5. Health system standards and guidelines

A programme to develop national guidelines has been in place since the early 1990s

There are a number of evidence based national guidelines produced by the National Board of Health and Welfare. The guidelines are intended to help health care providers to use resources efficiently, allocate resources where they are needed and make systematic and transparent decisions about setting priorities. In Sweden the development of guidelines is not just the activity of single professional disciplines but a system-wide effort to incorporate notions of evidence-based medicine, cost-effectiveness, multi-disciplinary perspectives and priority setting.

The emphasis is on developing guidance rather than issuing standards. In this respect this part of the work of the National Board bears similarities with the guideline and technology assessment programmes of National Insitutue of Health and Care Excellence (NICE) in England and the Haute Autorité de Santé (HAS) in France. As in these countries, Sweden relies on the input of formal technology assessment studies on cost-effectiveness such as produced by SBU. The idea is that these assessments form the basis for the setting of priorities within Swedish health care, acknowledging the local decision making freedom. There is also a national model for the transparent setting of priorities in health care.[6]

The first national guidelines were developed in the late 1990s (on cardiac care). To date, a number of new areas have been added: musculoskeletal disorders, disease prevention methods, dental care, lung cancer, schizophrenia, dementia, depression and anxiety, diabetes, stroke, cardiac care, substance abuse and addiction, breast, colorectal and prostate cancer and palliative care.[7]

Swedish guidelines are developed through a multidisciplinary consensus process

The National Board of Health and Welfare's selection of guideline topics is preceded by consultation with the county councils and the regions. Guideline topics are chosen based on the following criteria: existing differences in practice (for example identified through reports showing health inequality between countries), unclear state of knowledge, severe disease categories with major cost implications, number of citizens/patients concerned.

The National Board of Health and Welfare produces the guidelines in collaboration with external scientific and clinical experts. This gives the guidelines both high quality and high credibility. The external experts are also ambassadors for the national guideline in their respective organisations.

The National Board of Health and Welfare publishes the national guidelines in a preliminary version. The preliminary versions are then discussed in a number of regional seminars. The purpose of this is to give the regions the opportunity to both critically examine the guidelines and initiate their introduction.

Before the seminars, the regions carry out impact assessments based on the guidelines. These will form the basis for regions' decision-making processes on the action they should take in order to work in accordance with the recommendations. They will also form the basis for the National Board of Health and Welfare's continued efforts to finalise the guidelines.

Incentives are used to stimulate compliance with guidelines, coupled with regular monitoring and evaluation

For some activities recommended in guidelines, the government provides grants intended, among other things, to stimulate implementation of the guideline and encourage broader quality development in the particular clinical area addressed. New guidelines on dementia and schizophrenia, for example, were accompanied by such grants, disbursed to local government who were then free to use the additional funds as they best saw fit. The National Board of Health and Welfare conducts regular evaluations of compliance with the national guidelines, repeated after around three to four years and focused on those aspects of care deemed to have major need for improvement. The results of these evaluations are presented in the form of recommendations to the county councils, regions, hospitals and municipalities, and the goal is that the recommendations form the basis for local initiatives to improve the quality of care (see also Section 1.6).

The guideline programme executed under the guidance of the National Board seems of high quality and meets the various criteria set for guidelines internationally (such as those set out in the Appraisal of Guidelines for Research and Evaluation instrument).[8] Of special interest is the choice Sweden has made to link priority setting to the guideline agenda. It is also noteworthy that implementation and regular evaluation of compliance is an integral part of the programme. It might be of interest in future reports to address, complementary to the quantitative evaluation materials, more qualitative descriptions on the various challenges specific county councils/regions face with the implementation and the type of actions necessary to introduce change. This type of information could further facilitate the learning process and will help to distinguish the evidence that underpins the recommendations in the guidelines from evidence on effective implementation strategies on local level in Sweden.

1.6. Measuring and reporting on quality

Sweden has an impressive track record when it comes to measuring quality of care. This section discusses work around clinical indicators and registries, the systematic measurement of patient experiences and the various reports available in the public domain reporting on performance in the Swedish health care system.

Sweden has many indicators on clinical care, derived from a robust sets of clinical registries

Quality indicators are developed on several different levels and in different organisations. The National Board has been appointed the task to develop national guidelines, and one part of the process is to propose national indicators that reflect the performance of the care provider based on the guideline's key recommendations. National quality registers develop indicators for their specific diagnostic areas, and individual county councils and regions develop indicators for local follow-up work. Indicators with national status (for example those published in the national assessment reports and to some extent in the *Quality and Efficiency* reports (see below) are available over the internet from a data base administered by the National Board. The data base today contains over 800 indicators covering a wide variety of diagnostic areas and levels.

A recently formed unit at the National Board called Registry Service has been given the task to map the various data points collected through the national quality registers. This will be a valuable step to support development of new indicators and to ensure that the use of registries is not merely focused on scientific research but equally emphasizes the use of registry data for quality assurance and quality improvement.

A wide variety of mainly clinical indicators is available but indicators on social care are still scarce

Today, quality indicators have been developed for most areas of medical care. However, there is still much to be done regarding social care and the elements of medical care carried out by the municipalities. One important reason for the lack of indicators in social care is that routines for documentation and registration are different from that of medical care. Because of this it is much more difficult to collect information from the social care sector. Intensive work is taking place to improve relevant databases and use of quality indicators and to ensure that data are published regularly.

The indicators used today measure the quality in structures, processes, results, and the efficiency of Swedish health care. Most of the available data sources measure in-patient care and specialised out-patient care. A primary care register is currently being set-up by the National Board, and there are also a few social care registers, administered by the National Board, in use today.

The level of presentation of indicators with national status varies depending on the quality of data. It is often possible to present data on regional or county council-level, and sometimes also on unit level. When possible, the indicators reflect geographical, gender and socio-economic differences in the care provider's performance.

There are two main systems of collecting health care data. Some of the registers managed by the National Board have compulsory reporting from the care providers (such as the National Patient Register, Causes of Death Register, Prescribed Drug Register and a few others). Quality registers, in contrast, depend on voluntary reporting from care providers.

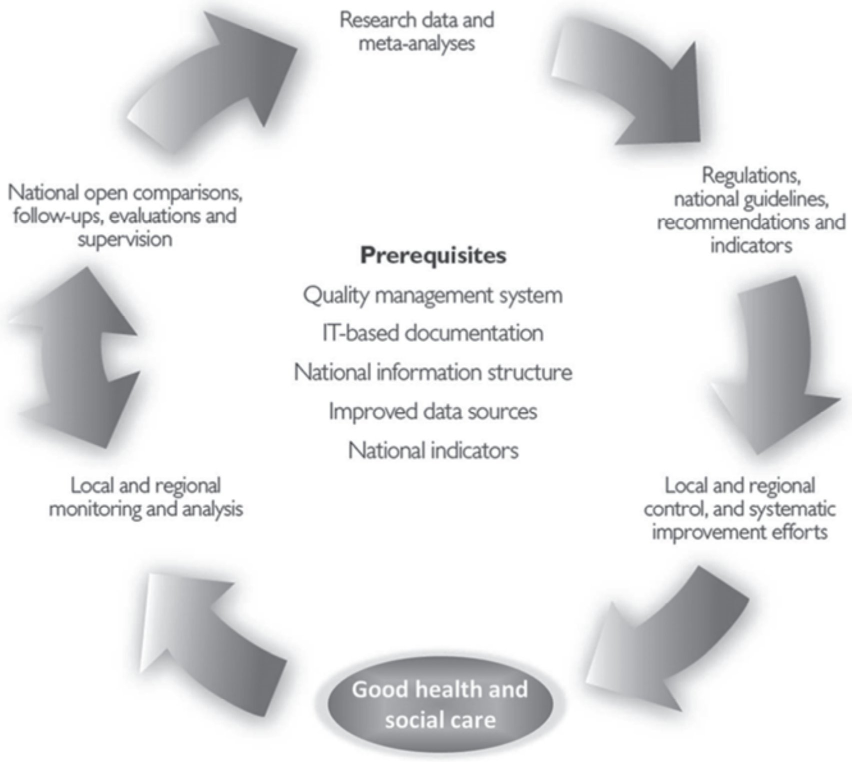
Mechanisms are in place to assure consistency in reporting to the registries via different levels in the health care system

The information flow from care providers to the quality registers is dependent, to some extent, on the reporting method used. Some quality registers use internet-based portals, whereas others still rely on paper-based surveys. This lack of common infrastructure means that the completeness and accuracy of quality reporting can vary across the different registers. Of note, though, financial incentives are sometimes used by county councils or other agencies to encourage a high level of reporting.

Information from the quality registers is used at different levels (national, regional, local, and unit level) to follow up on performance. All registers include a unique patient identifier (based on an individual's social security number). This allows, in theory at least, the linkage of data from different registers to obtain a richer picture of the care an individual receives. The extent to which this potential is fully exploited is considered further in Chapter 2.

The national model of knowledge management for good health and social care (Figure 1.1) describes how the different levels use information in the registers.

Figure 1.1. Knowledge management for good health and social care



Source: The National Board of Health and Welfare, 2012.

The quality registers are, without doubt, an important asset of the Swedish health care system. There are, however, limitations. The first concerns their scope: most registers are focussed on hospital care and incorporate services beyond the secondary care sector to a very limited extent. In particular, hardly any information on social care is typically included in a quality register. A related point is that the start and finish points of a care pathway are defined in purely clinical terms. Even if a patient's needs and care extend beyond a timeframe defined by acute clinical services, the quality of this on-going care is rarely captured by the quality registers. Third, heterogeneity of data collection also contributes to inefficiencies and variable completeness of data. Although work is underway to smooth the data-collection effort, a fully automated approach (based on unified electronic health record, for example) is not yet a reality.

1.7. Strengthening the role of patients by capturing patient experiences

Patients in the Swedish health care system have various opportunities to make an impact on health care quality. First, a set of national patient surveys and patient reported outcomes in the quality registers provide the health care system with feedback from the patients' direct experience of care, as described in more detail below. Additionally, patients who have had unsatisfactory experiences of care are advised in the first instance to contact personnel and managers responsible for the quality of care at the institution where the care was provided. The local Patient's Advisory Committee can support patients to do this.

If local resolution fails, patients are entitled to make a complaint to a special unit at the National Board called the Complaints Unit (*Enskildas klagomål*). The Unit then investigates and judges, on the basis of the current legal and regulatory framework, whether care has indeed be deficient and will authorise appropriate remedial action.[9] The recently created Health and Social Care Inspectorate will also have a role in ensuring an appropriate response to patient complaints.

Sweden has a long and well developed tradition in the systematic measurement of patient experiences

Sweden has a comparatively long tradition of measuring patient experiences systematically at national level. Since 2001, SALAR and the National Board have been developing methods for measuring patient experiences for use in planning and management of health care. At present, three approaches have been established: the National Patient Questionnaire, the Population and Patient Survey (*Vårdbarometern,* in Swedish) and patient reported outcome measures (PROMS) which are collected through the national quality registers. Each of these uses nationally standardised data collection and reporting methods.

In 2011 a new government agency The Swedish Agency for Health and Care Services Analysis (*Vårdanalys* in Swedish) was established. The main task of the agency is to analyse and evaluate implemented measures within the sphere of health and care service policy from the perspective of citizens and patients.[10]

The National Patient Questionnaire

The primary objective of the survey is to provide health centres, as well as hospital departments and outpatient clinics, with an instrument for measure and improve the quality of their care. Aggregated data are also used, however, to benchmark providers and regions. Since 2009, systematic measurements have been performed on a regular basis on primary care, outpatient and inpatient specialised care, emergency hospital care and outpatient and inpatient psychiatric care.

Questionnaires are conducted by SALAR on behalf of the Swedish county councils and regions,[11] with the aim of surveying the experience of primary care every two years and specialised care every two years. The questionnaire focusses on attitude of staff, participation in care decisions, and the information given to patients and their families. The results are intended to be used to develop and improve the care from a patient perspective.

The Population and Patient Survey

The Population and Patient Survey (*Vårdbarometern* in Swedish) is based on data collected through telephone calls with almost 42 000 randomly selected interviewees. The survey began in 2001 and operates annually across all regions, with the exception of Gotland. Its objective is to reflect the adult population's attitudes, knowledge and expectations of Swedish health care. Telephone interviews are based on a common nationally developed questionnaire, in some cases supplemented with county-specific issues.[12]

Patient Reported Outcome Measures (PROMs)

Over recent years, measurement of patient experiences has become an important element in Sweden's range of quality measurement and improvement initiatives. Several initiatives have been taken to improve the methodology underlying PROMs reporting. The National Board and SALAR have adopted complementary approaches in this respect. The former seeks to establish routine use of PROMs, including them as indicators in national guidelines when possible for example, whilst SALAR works in special projects to develop and improve both the measures themselves but also the infrastructure of collecting information.

As of 2013, several national quality registers use PROMs, typically based on validated instruments such as EQ-5D or SF-36. Example of medical areas where PROMs are used (web pages in Swedish):

- cardiac care (through the national quality register SWEDEHEART)[13]
- hip fracture care (through the national quality register *Rikshöft*)[14]
- breast cancer care (through the national quality register National Register for Breast Cancer Surgery)[15]
- rheumatism care (through the national quality register Swedish Rheumatology Register).[16]

SALAR also has a special task in promoting the use of PROMs in all the national quality registers in cancer care.[17]

International comparisons on patient experiences

Through its participation in the Commonwealth Fund survey and OECD Health Care Quality Indicator project, some aspects of Swedish patient experiences can be compared with other countries. As can be seen in the figures below, patients generally report positive about experienced communication and autonomy in ambulatory care services specifically related to the time spent for consultation (Figure 1.2), easy to understand explanations (Figure 1.3), opportunities to ask questions or raise concerns (Figure 1.4) and involvement in care and treatment decisions (Figure 1.5).

Although these data should be interpreted carefully (particularly given concerns around relatively small sample size), it is of interest to note that Sweden scores lowest on all four questions. Further work is needed to understand the extent to which Sweden’s low ranking reflects cultural values and expectations, or is a real reflection of differences in care quality across this set of countries. In either case, efforts at international benchmarking such as this underscores the importance of devoting sufficient attention to patient centeredness and patient involvement in contemporary health care policy.

Figure 1.2. Regular doctor spending enough time with patient in consultation, 2010 or nearest year

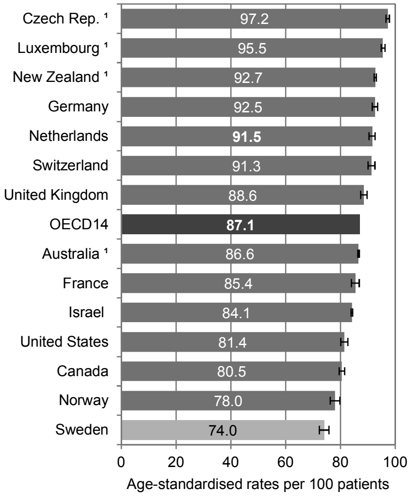


Figure 1.3. Regular doctor providing easy-to-understand explanations, 2010 or nearest year

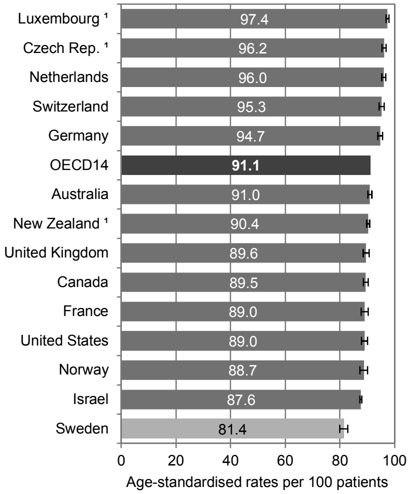


Figure 1.4. Regular doctor giving opportunity to ask questions or raise concerns, 2010 or nearest year

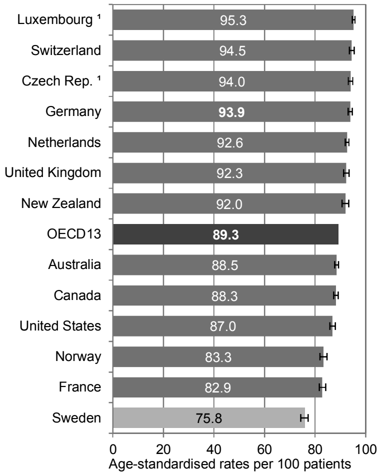
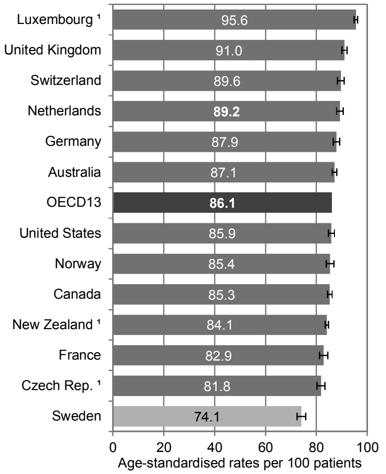


Figure 1.5. Regular doctor involving patient in decisions about care and treatment, 2010 or nearest year



1. Patient experience with any doctor.

Note: Rates age-sex standardised to the 2010 OECD population. 95% confidence intervals represented by H.

Source: The Commonwealth Fund International Health Policy Survey 2010 (www.commonwealthfund.org/Surveys/2010/Nov/2010-International-Survey.aspx) and other national sources.

1.8. Public reporting of performance

As previously described, the national knowledge management model for health care is used by authorities and care providers to describe the different steps and responsibilities in knowledge management (see Section 1.3). The purpose of the local/regional monitoring is to make sure that resources are used in the most efficient way and quality is assured. The nationwide monitoring and evaluation instead has a more comprehensive purpose. There are a number of different types of national reporting activities conducted by different authorities and organisations. Two examples are described below.

The Quality and Efficiency in Swedish Health Care publication is a simple and effective tool that drives quality improvement

This is a yearly report that serves as a well-used source of information for the care providers at different levels. The report is the result of collaboration between the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions (SALAR), and is commissioned by the Swedish Government. The first report was published in 2006 and the reports are also available in English. The first purpose of the report, which transparently publishes comparative data about health care performance, is to inform and stimulate public debate about health care quality and efficiency. The second purpose is to stimulate and support local and regional efforts to improve health care services.

Data for the report is collected from a wide range of national quality registers as well as from the health care registers managed by the National Board. All such registers include unique patient identified data, which in Sweden is based on an individual's social security number.

The report gives an overview of regions', county councils' and hospitals' achievements in a wide range of diagnostic and health care areas. The report does not analyse reasons for geographical, gender and socio-economic differences, nor does it give specific suggestions as to how quality differences between the regions, county councils and units can be reduced. Instead the different recipients of the report are expected to analyse the results themselves bearing in mind what local/regional factors that may influence the results.

The latest report, published in 2013, included 169 indicators. In 2011 a *Quality and Efficiency* report specifically focusing on cancer care was published as well. Similar open comparisons of quality and efficiency are published in the areas care of the elderly, support to persons with disabilities, child and youth welfare and several other areas.

National Assessments offer more in-depth analysis of particular areas of care

In-depth national assessments of a defined area of care are conducted by the National Board and aim to offer a richer analysis that possible in *Quality and Efficiency in Swedish Health Care.* An assessment report typically examines 20 to 60 guideline-specific indicators, largely from relevant quality registers although other appropriate sources are used as well. Data is presented on different levels (national, regional, county council and unit for instance hospital) as well as being disaggregated by age, gender and socio-economic status (such as educational level). In an appendix to the main report the county councils' and units' results are presented as profile graphs showing their achievements relative to the national mean value per indicator. For each county council a summary of what areas need to be improved is compiled and measures to be taken in order to increase the quality of care are recommended. The assessment also results in national recommendations to the care providers focusing on indicators where performance appears poor.

There is a close relationship between national guidelines and the national assessment reports outlined above, the guidelines forming the basis for the indicators used in the assessment reports. This means, however, that only areas with national guidelines undergo assessment assessments – a distinction which is drawn out in Chapter 4 when comparing the quality architecture surrounding stroke care and care after a hip fracture. So far *National Assessments* have been published for cardiac care (available in English), psychiatric care, stroke care and diabetes care. During 2012 and 2013 National Assessments will be published for psychiatric (an update), dental, cancer, dementia and cardiac care (also an update).

Several other reports containing information on quality and efficiency are published every year. The National Board and SALAR both publish public reports based on health care data, the national quality registers publish yearly reports within their specialty, and several patient organisations and foundations collect and publish data as well. Emphasis, however, is on clinical aspects and health care services and less on social care.

Mechanisms to assure the quality of reporting and interpretation are in place

Since every patient receiving inpatient care or specialised outpatient care (hospital-based) is reported to the national Patient Register it is possible to compare specific quality register's rates of coverage with the national Patient Register, i.e. the percentage of patients reported to both registers. In

National Assessments only information from quality registers with a high degree of coverage are used for formulating national recommendations. In the *Quality and Efficiency of Swedish Health Care* report, information from quality registers with a lower degree of coverage is included as well, with the purpose to stimulate the care providers to a higher reporting rate to the register.

During the process of analysing the collected information, all data as well as interpretations are discussed with the register holders to ensure that it is correct. By doing so the risk of incorrect data due to technical issues or delivery methods is reduced. The use of external experts to help interpret and comment on indicator outcomes is necessary to ensure the quality of reports published by the National Board. The experts are always specialists within the specific diagnostic area assessed and declare any conflicts of interest before participation.

Given that *Quality and Efficiency of Swedish Health Care* is the result of collaboration between the National Board (representing the government) and SALAR (representing the care providers), the latter are involved in choosing which indicators are presented and in contributing to their interpretation. In contrast, the involvement of care providers in preparation of the *National Assessments* is more limited. Here, the National Board informs care providers of what types of care are being assessed and which indicators are used. The intention is to ensure an assessment that is independent from any political interests.

Is performance information used by consumers, financers and providers of care?

Being a regularly published overview of performance in a large number of diagnostic areas, the *Quality and Efficiency* report is a well-used source of information for care providers at different levels. The information is used for local and regional planning and prioritisation, but also for actual development and improvement at provider level. The report also generates substantial media interest and stimulates public debate on health care quality and efficiency.

The *National Assessments* are primarily directed to decision makers (both elected representatives and public officials) in government, regions and county councils and as well as to local health care management. The close connections to the national guidelines make these reports especially useful as instruments to monitor local and regional implementation of the guidelines' recommendations. In addition to the published report, the National Board also offers to discuss with individual regions and county councils results during regional seminars as a way of adding a dimension to the analysis in the report.

Pertinent to both products, the fact that all information regarding health care provider's performance is transparent and made public increases the interest from the health care providers to actually use the information for improvement. They are aware that their efforts will be monitored regularly, and that the public expects them to improve in areas where the results are not up to standard.

Information ownership

The registers used to monitor and evaluate Swedish health and social care have different owners depending on their status. Registers with compulsory reporting from the care providers are administered by the National Board commissioned by the Swedish parliament by means of legislation; no "owner" is specified for those registers. The national quality registers on the other hand are owned by the county councils. Typically, each quality register is owned and administered by one specific county council.

Most of the information from the different reports mentioned above is published on the internet. Most information from the *Quality and Efficiency* publication and from the national assessments is also available in a searchable database that is accessible for the public on the internet. This database enables the user to present the information in different ways, and to make individual selections depending on what level of presentation is of interest. Some information is not published on the internet, or at least not on unit level. One reason for this is to minimise the risk of individual patients being identified due to small number (i.e. few cases registered). Patient integrity is thus an overriding consideration before any information is published.

1.9. Health system improvement

As made evident in the preceding sections, Sweden has made a clear effort to improve health care quality through a continuous cyclic process of standard setting, monitoring and actions. Although it is difficult in the context of an external quality review by the OECD to assess the magnitude of the actual use of the provided information for quality improvement activities, the impression is that this model serves the devolved responsibilities for health care services in the Swedish health care system well. Counties have taken up their own responsibilities and some of them, like the county of Jönköping, have a track record in system wide quality improvement for more than 15 years (Box 1.2).

Box 1.2. Experiences with system wide quality improvement in Jönköping County

Jönköping County Council in southern Sweden governs health services for a population of about 330 000. For more than 15 years the leadership at Jönköping has pursued an ambitious agenda of improving quality of care while limiting increases in the costs of that care. The vision of the Jönköping County Council is “a good life in an attractive county” reflecting the goals of a holistic vision focused on quality of life, not just the delivery of care. (Øvretveit and Staines, 2007).

Jönköping first drew international attention from its participation in Pursuing Perfection, an eight-year demonstration project sponsored by the Robert Wood Johnson Foundation and directed by the Institute for Health care Improvement (IHI). Pursuing Perfection involved seven US health systems along with a number of international health systems in an ambitious multi-year programme to create system transformation, improving care across the continuum. Each of the US systems received a large grant from the foundation, while the international systems (from England and the Netherlands as well as Jönköping) were self-funded.

Coached by international experts in quality, these health systems worked to identify, implement and sustain new innovations and improvements, engaging frontline clinicians and leaders. Jönköping focused on systems improvements across the three hospitals and 34 primary care centres in their county and achieved improvements in virtually all sites, improving patient flow, asthma care, elder care, children’s servicers, prevention of influenza and patient safety. This work streamlined care process across the system, producing substantial savings as well as improvements in care (Baker et al., 2008, pp. 1234). Donald Berwick, then the CEO of IHI, lauded Jönköping’s efforts, identifying them as leaders among this highly regarded set of health care systems in Pursuing Perfection (Berwick et al., 2005). Later analysis in Sweden suggested that substantial savings would be possible across Sweden if the strategies and methods identified and implemented in Jönköping were spread among all Swedish counties (Cederqvist, 2005).

Compared to the other 20 county councils in Sweden, Jönköping achieves the best overall ranking on indicators across Sweden’s six goals for quality, namely: efficiency, timeliness, safety, patient centeredness and equity, and effectiveness (Jönköping County Council 2005).

Source: Based on Ross Baker, G. (2011), *The Role of Leaders in High Performing Health Care Systems,* Kings Fund, London.

This final section of this chapter analyses the activities that take place as part of measuring and improving patient safety. As with clinical effectiveness and patient experiences, large efforts are made to turn this into a cyclic activity. However, concerns on patient safety are perhaps even a stronger public concern than clinical effectiveness and patient centeredness; hence here the national role seems slightly more dominant although remain closely linked to local activities.

1.10. Patient safety

In 2008 the National Board of Health and Welfare published a study on the incidence of adverse events in Swedish hospitals, carried out on hospital admissions from October 2003 to September 2004. The aim of the study was to estimate the incidence, nature and consequences of adverse events, and preventable adverse events in Swedish hospitals.

The results of the study have been instrumental in the Swedish Government's initiative on reducing preventable adverse events causing patient harm. The government has made an agreement with SALAR on annual reporting of results of specific requirements and indicators within the patient safety area, including financial rewards to regions that reach agreed goals. The agreement covers the period from 2011 to 2014.[18]

Swedish initiatives on patient safety: the role of SALAR and the National Board of Health and Welfare

SALAR has developed eight care bundles in order to prevent adverse events covering health care associated urinary tract infections; central line infections; surgical site infections; falls and fall injuries; pressure ulcers; malnutrition; medication errors in health care transitions; and drug-related problems. SALAR also publishes three handbooks for patient safety improvement: failure modes and effects analysis and root cause analysis; Patient Safety Culture Survey; and Retrospective Medical Record Review. SALAR has also undertaken national point prevalence measurements of health care associated infections, pressure ulcers and compliance to basic hygiene routines and clothing rules. This function will be taken up by the recently created Health and Social Care Inspectorate.

The National Board of Health and Welfare issues various formal statements in order to promote patient safety. The requirements in these statements are similar to those covered in standards that are used in international accreditation programmes. These formal statements constitute an important basis for the National Board's supervision of health care services. The Board is also responsible for the licensing of health care personnel. In addition to these roles the Board is commissioned by the government to perform various specific tasks related to patient safety, for example to assess the results of the agreement between the government and SALAR, to produce annual patient safety reports and to propose a national patient strategy.

Health care organisations are required to have adverse event and risk reporting systems in place and health care personnel are required to report adverse events and risks. In addition, health care organisations are required to perform risk analyses and document the results. This information is used by the organisations themselves to improve their services. Health care organisations are required to report sentinel events to the relevant national authorities (as of June 2013, the Health and Social Care Inspectorate), which supervises that these events are adequately investigated and that appropriate actions are taken and publishes periodic analyses of trends and policy responses. Some 1 500 sentinel events are reported annually; patients and their next of kin are entitled to report risks and adverse events.

Health care organisations are obliged to report to the National Board if health care personnel's behaviour for any reason presents a threat to patient safety. The National Board supervises that the health care organisation takes appropriate actions. If the National Board deems it necessary it can withdraw a license or institute corrective actions, the National Board can also make an appeal to a special court. In addition, pharmacies are obliged to notify the National Board if they have reason to believe that a narcotic prescription is inappropriate. The Board also has access to the national prescription registry.

National procedures for reporting adverse events and errors are in place

It is stipulated in the Swedish Patient Safety Act that health care providers must investigate incidents that have caused or could have caused a health care injury. The aim of the investigation is to establish the course of events and what factors have influenced it, and provide an information-base for decisions on activities with the aim of impeding the reoccurrence of similar incidents or to limit the effects of such incidents if it is not possible to prevent them completely.

In the case of serious injuries, the provider is also required to notify the national authorities (as of June 2013, the Health and Social Care Inspectorate) as soon as possible after the incident has occurred. This information is used both to ensure that the provider has taken the necessary measures to prevent the incident for the future, as well as to inform other health care providers about the incidents.

Mechanisms for handling medical malpractice are in place

Reports about medical malpractice are also investigated by the National Board of Health and Welfare. The National Board can also, based on findings from doing supervision at hospitals and other health care providers, investigate doctors and other health care personnel.

Health care providers and pharmacies are obligated to report health care personnel who might be endangering patient safety. In the law several detailed provisions are made to regulate the reporting, investigation and handling of malpractice of health care professionals in Sweden.

Safe care is rewarded

In December 2010, the national government and SALAR reached a "pay for performance" agreement in order to promote patient safety. The agreement covers the period from 2011 to 2014. Each year, a set of criteria and goals are defined that, if meet by a county council/region, triggers release of additional funds from the national government. The yearly sum available is in the order of EUR 60 million. Examples of topics (indicators) included in the agreement are measurement of; patient safety culture, pressure ulcer prevalence, compliance to basic hygiene routines and clothing rules, hospital overcrowding; use of retrospective medical record review to assess the rate of adverse events and a reduction in the prescription of antibiotics to out-patients.

1.11. Conclusions

Sweden has a well-developed quality management model in place to address the assurance of clinical effectiveness, patient centeredness and patient safety. The quality management model relies on a combination of national guidelines, an extensive system of reporting based on quality and efficiency indicators as well as the respective roles of the National Board of Health and Welfare and local governments. The capacity of local health care systems to react to the feedback by realising their responsibilities for quality assurance and quality improvement is particularly critical. Within these broad arrangements, the main challenge is to achieve a "full cycle" approach towards quality improvement and a broadening of the scope from clinical care towards services provided in primary care and social care.

To strengthen and broaden this cyclic model it seems advisable to align the roles of the various national government agencies towards quality of care, clearly distinguishing the functions of standard setting, monitoring and improvement and addressing professionals and organisations as well as local health care delivery systems (health care and social care). Both the triple functions (standard setting, monitoring and improvement actions) and the triple focus (professionals, organisations, local integrated care delivery systems) ask for a coherent and consistent quality management approach in a devolved governance model as the Swedish one.

Creation of the Health and Social Care Inspectorate in June 2013 seems a sensible step. Beyond this though, introduction of a more formal process for assessing individual professional performance and processes to assure the quality of specific health care organisations (accreditation) should be considered to complement the existing quality strategies. Local freedom to tailor improvement actions should be matched with clear national standards on health system inputs such as health care professionals, health care organisations and drugs and technologies. Likewise, accountability mechanisms through indicators can be complemented with more qualitative information on local health system change to facilitate spread of improvements in health and social care across counties.

In short, Sweden seems to balance in its quality strategies a formative with a summative approach executed through a devolved governance model. To develop the model further, both strengthening some summative aspects (re-certification professionals and accreditation of health care organisations, for example) as well as formative aspects (such as shared learning across counties on local health system improvements) are recommended.

In addition, Sweden has the unique opportunity to broaden its existing activities, mainly focusing on local and regional health care systems, towards such a national quality and safety approach where the underlying data sources are identical and mutual synergy and efficiencies can be achieved. Whist the present system of registries is impressive, it could be broadened to include primary care and social care more fully, thus ensuring comprehensive monitoring of local health system performance.

Over the longer term, an information strategy that links data collection for registries to electronic health records would be desirable and Sweden is one of the OECD countries that is well suited to make this happen. Strategies on e-health should keep on addressing the optimisation of data use for reporting quality measures.

Activities of systematic measurement of patient experiences are impressive but should especially be broadened to long-term care with a focus on integration and continuity hence broadening the present focus on the assessment of clinical care to the assurance of integrated health care services. Furthermore, this type of information should be promoted to be used actively in the further involvement of Swedish citizens in the local design, evaluation and improvement of health and social care services.

Notes

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2. http://ec.europa.eu/internal_market/qualifications/policy_developments/legislation_en.htm.
3. www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Patientsakerhetslag-2010659_sfs-2010-659/; www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Patientsakerhets forordning-20_sfs-2010-1369/.
4. www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Patientsakerhetslag-2010659_sfs-2010-659/.
5. MPA:s English web site: www.lakemedelsverket.se/english/
6. www.imh.liu.se/halso-och-sjukvardsanalys/prioriteringscentrum/publikationer/prioriteringscentrums-publikationer-ovrigt-publicerat-material/1.291196/2011-4_utskrift.pdf.
7. Link to translations of summaries of national guidelines: www.socialstyrelsen.se/nationalguidelines; Link to national guidelines: www.socialstyrelsen.se/riktlinjer/nationellariktlinjer.
8. www.agreetrust.org
9. For more information please visit the website; www.socialstyrelsen.se and www.socialstyrelsen.se/klagapavarden.
10. www.vårdanalys.se/.
11. www.skl.se/vi_arbetar_med/halsaochvard/kvalitetsutveckling/nationellpatientenkat; http://npe.skl.se/.
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Chapter 2

Primary care and care co-ordination in Sweden

Indicators of health, health care quality and long-term care for the elderly in Sweden are among the best internationally. The Swedish health care system now faces the challenge of delivering high quality, user-centered and well-co-ordinated services, while coping with the pressures common to most developing countries of an ageing population, growing prevalence of chronic disease and budgetary constraints. Primary care's role in preventing and managing the burden of chronic disease, and in co-ordinating care across services and providers, will be critical to meeting this challenge.

While health and social care policies are broadly defined by the central government, Sweden has a highly devolved care system. Lead responsibility for the funding, organisation, management and delivery of health care services rests with the 21 county councils and regions, and of long-term care for older people with the 290 municipalities. While health and social care services in Sweden are generally of a high standard, divided administrative responsibilities for care mean that no single agency is responsible for care co-ordination. Government reforms introducing patient choice and competition in primary care also have implications for primary care's de facto role in care co-ordination.

This chapter examines the organisation of primary care in Sweden and how well prepared it is to meet emerging challenges, especially those of prevention, chronic disease management and care co-ordination across multiple service providers. We also consider how Sweden's skilled primary care sector can be further developed to improve the quality and co-ordination of care for the Swedish population.

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

2.1. Introduction

In common with most developed countries, longevity and the numbers of people with chronic disease who need long-term health and social care are rising in Sweden on account of population ageing and technological advances in medicine. These pressures on the demand side, compounded by the unprecedented financial constraints facing most countries, are major challenges for the Swedish health care system in delivering high quality care and meeting rising patient expectations. The concomitant need for services that are well-co-ordinated, both within and across health and social care, and covering the full spectrum of services from prevention and early diagnosis to treatment of established disease, provision of long-term health and social care, and services for palliative care, is an additional challenge for the Swedish primary care sector.

Sweden's population is elderly and ageing. The proportion of the total population aged 65 years and over (19.3%), and 80 years and over (5.5%), is fourth highest among the OECD countries (*OECD Health Statistics 2013*). These proportions are expected to rise to 24% and 10% respectively by 2050. There is also a geographical component to this demographic issue – the northern counties of Sweden are ageing more rapidly than the rest of Sweden because of outward migration of young people. These counties are also more rural, sparsely populated across large areas, and they experience staff shortages and recruitment difficulties, posing additional challenges to the provision of health care.

With an ageing population, growing burden of disease and multi-morbidities, and no significant change in funding or the workforce anticipated, Sweden faces the challenge confronting all developed economies of how to deliver more with less and without compromising quality. Restructuring of the hospital sector into fewer, more specialised units, transfer of care from hospitals to the community, and the quality and cost pressures to reduce hospital admissions, are also placing increased demands on primary care to play a more proactive and ambitious role in the delivery and co-ordination of health care.

The significant contribution that primary care can make to improvements in population and individual health, and reductions in health inequalities and health care costs, are well documented and apply over time and across health systems (Starfield et al., 2005; Kringos, 2012). Countries with health care systems based on a strong primary care sector have better health at lower costs. The unique features of primary care identified by Starfield include first contact access and use of primary care services; person rather than disease focused care over time; comprehensiveness of services provided within primary care; and care co-ordination. A coherent primary care system, with general practice as its integrative core, has the potential to improve the quality, co-ordination, responsiveness and cost-effectiveness of health care services (Shi et al., 2002; Boerma et al., 1998).

Sweden's health care system is founded on a well-organised and comprehensive primary care sector, and most patients enter the health care system via primary care. The sector is therefore well placed to play a prominent role in reducing the disease burden and improving care co-ordination and integration. With growing pressures on the demand for and supply of health care, the Swedish Government aims to enhance the role of primary care, including in secondary prevention and care co-ordination, while simultaneously promoting its reform agenda of offering patients their choice of provider and competition among providers.

This chapter examines the organisation of primary care in Sweden, the reforms underway, the achievements of primary care to date, and how well prepared primary care is to meet the emerging challenges, especially in terms of managing the burden of chronic disease and co-ordinating care across multiple service providers. We also consider how Sweden's well-developed primary care sector can contribute further to improvements in the quality and co-ordination of care for the Swedish population.

In this chapter primary care is defined as the community-based, physician-led clinics that provide generalist medical care to local populations, including health promotion and preventive interventions, and a broad range of community-based specialist services. The primary care sector sits alongside national public health programmes for health protection, health promotion and prevention, which are not discussed here.

2.2. The configuration of primary care in Sweden

Sweden's model of primary care offers good development potential for the future

In Sweden responsibility for primary care rests primarily with the 21 county councils and regions. Long-term care for older people living at home, in care homes or nursing homes, and for those with disabilities or long-term mental health problems, is the responsibility of the 290 municipalities. Primary health care is generally the route of entry into health care for Swedish patients, and for signposting to services. However, registration with a primary care physician or practice is not compulsory and, in contrast to many countries with a national health care system, primary care in Sweden has no formal gate-keeping role; patients are able to, and sometimes do, access specialist care directly (Paris et al., 2010). Sweden is one of the few EU countries without a national system of gate-keeping (Masseria et al., 2009).

Sweden has a comprehensive, national network of about 1 200 public and private primary health care centres covering the country, about 40% of which are privately owned. Since the 1970s, Sweden has encouraged large "one-stop shop" clinics where patients can access both GPs and specialists, and some diagnostic and laboratory services, thereby enhancing the range of services available to patients outside hospital (Masseria et al., 2009). Typically, primary care in Sweden comprises physician-led clinics providing medical, preventive and rehabilitative care that does not require the medical and technical facilities of a hospital. They tend to be multiple partner establishments, each staffed by a group of GPs and a multidisciplinary team including nurses (many of whom are specialists in e.g. diabetes, paediatrics, etc.), physiotherapists, midwives and psychologists, providing a wide range of medical services. There are national guidelines for smoking, alcohol use, physical activity and diet; primary care staff are expected to counsel patients on these lifestyle habits and offer advice, support and referrals.

GPs, jointly with hospital, outpatient and social care staff, are also responsible for post-discharge care planning and developing care plans for rehabilitation and follow-on care. For patients requiring long-term care, responsibility for the patient is transferred to the municipality once a care plan has been developed. Responsibilities and arrangements for primary care in the context of long-term care for the elderly are variable.

Practice nurses and other (non-GP) practice staff play a significant role in frontline care delivery, and are often the first point of contact with the health care system. In 2009, there were 40 million primary care visits, corresponding to 4.3 visits per person (Anell et al., 2012). Of these, 14 million visits were with GPs, 1.5 per capita, compared with 2.67 visits with other practice staff, predominantly nurses. This shift of workload from GPs to other practice staff reflects developments in primary care elsewhere. For example, in England the proportion of consultations undertaken by practice nurses increased from 21% to 35% between 1995 and 2008 (Goodwin et al., 2011). Sweden was one of the first European countries to create nurse-led clinics for patients with long-term conditions, such as diabetes and heart failure (Masseria et al., 2009). Nurses also play a role in care co-ordination for chronically ill patients, and have a limited role in prescribing.

People with minor mental health problems are usually attended to in the primary care setting, either by a GP or by a psychologist or therapist.

Patients with serious mental health problems are referred on to specialist psychiatric care in hospital.

Historically, health care in Sweden was characterised by an under-provision of GPs and primary care facilities, low usage of primary care services, and long waits. Structural reforms in the hospital sector over the past decade, with a reconfiguration of hospitals into larger, specialised establishments, and an action plan in 2000 to strengthen primary care, have resulted in a more prominent role for primary care. With an expansion in GP numbers and primary care centres, and more care being delivered in the community, there has been a significant reduction in hospital numbers, beds and length of stay. Sweden now has significantly fewer hospital beds per 1 000 population (2.7) than the OECD average (5), and shorter lengths of hospital stay (5.7 and 7.2 days respectively) (OECD, 2013).

In an analysis of the input-output efficiency of primary care service delivery across 22 countries, Sweden was one of the few countries found to be efficient at turning both organisational structures (governance, economic conditions, workforce development) into care delivery processes (access, comprehensiveness, continuity, co-ordination), and processes into quality outcomes (prescribing, quality indicators) (Pelone et al., 2013).

Like other developed economies, Sweden's care system faces the double jeopardy of financial constraints combined with increasing care demands because of population ageing and rising public expectations. It is therefore imperative that primary care's role in preventing and managing ill health, and in care co-ordination, is strengthened, in order to further improve quality and reduce the use of hospital services. As a central, readily accessible, community-based care provider offering a comprehensive range of services by a multidisciplinary complement of skilled staff and operating from well-equipped facilities, primary care in Sweden fits the model that many countries aspire to. These attributes mean that it is potentially very well placed to play a frontline role in meeting the epidemiological and financial challenges that lie ahead.

Funding arrangements vary locally, but cost is not a significant barrier to access to primary care services for patients

Historically, health care spending in Sweden was characterised by a focus on hospital and specialist care, relative under-investment in primary care, and a shortage of GPs. Growth in health expenditure was contained for many years by budgetary controls, the application of cost-effective health care technology assessments, controls on the overall numbers of health personnel, and then the reconfiguration of services through restructuring of the hospital sector and expansion of primary and community care. Since the

1990s, in parallel with the hospital reforms, the government has moved to strengthen the role of primary care, including through increased investment and periodic supplementary grants to county councils to support, for example, the development of primary care, care for older people, psychiatric care, reduced waiting times, patient safety, cancer care and improved care co-ordination. The per capita cost for primary care in 2011 averaged SEK 3 580, corresponding to 17% of total health care costs (Swedish National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, 2013). Expenditure on primary care varies between counties, in part due to differences in geographical conditions that impact on costs e.g. several sparsely populated counties have inpatient beds in primary care facilities.

Sweden's long tradition of self-government and devolved system of administration means that the organisation, funding, delivery and governance of services is largely determined locally and differs between councils and between municipalities. Primary care is funded through a mix of capitation payments, fee-for-service and user charges, with pay-for-performance payments playing a modest role. The relative contribution of these funding routes differs locally. For example, in Stockholm county council about 40% of the payment is based on capitation, 55% on variable fee-for-service, and 3% is performance-related. In other county councils, between 80-98% of the payment is based on capitation. The risk-adjusted formulas used for determining capitation payments also vary between counties, from simple formulas based on age and gender to more complex formulas incorporating health status, prior use of services and socio-economic need.

Although pay-for-performance payments constitute a relatively small component of overall funding for primary care, they are much sought after by councils and municipalities. Such schemes include government or locally funded incentives for attaining specified priorities. Examples of indicators used for performance-related payments include national waiting time targets, preventive services, patient experience, registration in national quality registers and efficiency (e.g. prescribing of generic drugs).

Capitation payments reportedly carry the risk of cherry-picking of patients, skimping, under-provision of care and cost-shifting. Fee-for-service payments, on the other hand, are said to provide little incentive to improve the quality of care and reduce use of services. The government's expectation is that the reforms in primary care – with their focus on promoting choice, competition and transparency, supported by performance-related incentives – will reduce these negative effects and improve the access, responsiveness, quality and value for money of services.

In Sweden user charges are levied for visits to physicians and for pharmaceuticals, but they are low relative to many countries and are subject to ceilings. Overall, out-of-pocket payments comprise 17.2% of total health expenditure, lower than the OECD average of 19.8% (*OECD Health Statistics 2013*). The fee for consulting a primary care physician varied between EUR 11-22 in 2011 and consultations with a nurse are free (Anell et al., 2012), a pricing structure that encourages the use of staff other than GPs and which could account in part for the greater use of practice staff relative to GPs described earlier. The national ceiling for out-of-pocket payments for health care visits within a year is EUR 122 annually. Co-payments for prescribed drugs are regulated by government and are uniform throughout the country. Patients pay the full cost of prescribed drugs up to EUR 122, after which the subsidy gradually increases to 100%. The maximum annual co-payment for prescribed drugs is EUR 244. With Sweden's legal and political commitment to universal access to health care for all residents, low user charges and minimal use of private health insurance, cost does not appear to be a major obstacle to accessing primary care.

A shortage of GPs and lack of formal professional development schemes could present obstacles in harnessing the full potential of primary care

There were about 5895 GPs in Sweden in 2010, a ratio of 0.63 per 1000 population (*OECD Health Statistics 2013*). This is a significant increase from about 2 000 GPs a decade ago, when access to primary care was constrained by limited capacity and a shortage of GPs, leading patients to rely more heavily on outpatient and specialist services. Even up to 2006, Sweden had fewer GPs and higher patient list sizes than many countries (Masseria et al., 2009).

The shift from hospital to community-based care has increased workloads on primary care and GPs, especially in caring for patients with complex conditions and reducing hospital admissions in an ageing population. An overall shortage of 1 000 primary care physicians is reported, including a shortage of specialists in geriatric care, and there are recruitment and retention problems in rural, sparsely populated areas. Sweden aims to increase GP numbers to reach a more favourable GP/population ratio, in order to safeguard the quality of care and maintain an acceptable working environment for primary care personnel. Such a shift would mirror, for example, trends in England, where the number of patients per (full-time equivalent) GP fell from 1 780 in 2001 to 1 562 in 2011, paralleled by a move towards larger practices employing more GPs and with larger list sizes (NHS Health and Social

Care Information Centre, 2012). Although there are inconsistencies in the various sources of information about GP numbers in Sweden, comparisons with some Nordic countries show that the number of inhabitants per physician in general practice in 2009 was higher in Sweden (1 563) than in Norway (868), Finland (981) and Denmark (1 063) (Nomesco, 2011). That said, international comparisons historically suggest that GP workloads in Sweden were low relative to many countries (Groenewegen et al., 2004; Boerma, 2004; Rae, 2005). Thus the evidence on GP numbers and their workloads is mixed, and it is unclear what the current position is.

Workforce data, including on GP numbers, are not centrally available in Sweden, as workforce planning and recruitment is largely determined locally by county councils. From the information available, it seems likely that Sweden will need more GPs if primary care is to take responsibility for an increasing share of care provision and co-ordination. A nursing shortage is also forecast, because of drop-out and retirement effects.

Swedish GPs are medical specialists in Family Medicine on the same level as other specialists. They undergo a medical training period of five years, followed by a 21-month training period in general medical care, and another five years of study if they decide to specialise. (The terms "general practitioner", "family physician" and "district physician" vary locally, but all refer to specialists in general medicine within primary care.) Primary care staff, in both public and private health centres, are predominantly salaried employees.

After completing training, GPs can apply to the National Board of Health and Welfare (NBHW) for a licence to practise. Licences are not time-limited and GPs do not have to re-apply to keep their licence. As with other health care staff, there are no formal, national systems of continuous medical education and professional development for GPs and other primary care staff, or for recertification. Consistent with Sweden's culture of local empowerment, trust and shared values, this agenda is not nationally mandated. The responsibility for continuing professional education for all employed medical staff rests with the employers, i.e. county councils, municipalities and private providers. It is unclear whether these ad hoc, local arrangements offer adequate opportunities for up-skilling GPs and other primary care staff, including in providing and co-ordinating care for the growing volume and complexity of physical and mental health needs of an ageing population.

Inadequate data on quality in primary care is an obstacle to improving the quality of services and care co-ordination

The information architecture for primary care is less well developed relative to the rest of the Swedish health sector, resulting in a dearth of comparative data on quality in primary care to effectively support functions such as benchmarking for quality improvement, quality assurance, patient choice, and care co-ordination. Although the Swedish health care sector has advanced IT systems, and 100% of primary care providers have electronic patient records, several different IT systems are in use and there is a lack of uniform information standards and classifications. County councils, regions and municipalities use different information systems and have adopted different IT solutions that are not always compatible across or even within county councils and levels of care.

As noted in Chapter 1, quality registers are the main source of information about health care quality in Sweden. While there is ample evidence of the use of quality registers for quality improvement in hospital and specialist care, there is less evidence of their application in primary care. In common with the way clinical audits have traditionally developed in many countries, quality registers in Sweden focus predominantly on hospital and specialist care. Eight of the 73 quality registers also cover services provided in primary care: dementia, diabetes, heart failure, chronic obstructive pulmonary disease (COPD), palliative care, slow-healing wounds, asthma and Senior Alert (for reducing falls, malnutrition, pressure ulcers). However, in general, coverage of providers and data completeness in quality registers is considerably poorer in primary care than for the hospital sector.

Although the government offers some financial incentives to county councils to encourage providers to register for data submission to the national registers, participation in the registers is voluntary and variable; consequently data coverage in primary care is incomplete. In part this is reportedly because staff find the add-on task of data collection and reporting for several quality registers burdensome, resulting in weak engagement by GPs. Coverage varies across the quality registers with some registers, for example in psychiatry, being very incomplete. Coverage of the dementia register is reported to be 50% of estimated incidence, and reporting by primary care units is 50%, although it is rising steadily. Even for quality registers with high overall participation rates, such as those for diabetes and cardiovascular disease, coverage in primary care can be significantly incomplete compared with data submission by hospitals (Swedish National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, 2011).

The quality registers are also mainly vertical and disease-based, and therefore unsuitable for managing the growing prevalence of multi-morbidities. Evidence from the United Kingdom shows that 42% of patients registered in general practice have one or more long-term conditions, and 23% have multi-morbidities (Barnett et al., 2012). The focus of national guidelines and quality registers on specific conditions is not unique to Sweden; it reflects the global lack of evidence on quality standards for the management of patients with multiple, complex care needs. But it does highlight the need for alternative strategies and improved continuity of care for such groups of patients (Roland and Paddison, 2013), as discussed later in this chapter.

As quality registers are the main source of data on quality in Sweden, the overall consequence of these issues is inadequate information about quality in primary care. This may in part explain why there is less evidence of a culture and bottom-up led initiatives of using data for quality improvement in primary care, in contrast to hospital and specialist care where the use of quality registers for quality improvement is much better embedded. The government incentivises submission of data to quality registers, and grants for developing new registers for primary care are being introduced. But there is a way to go before comprehensive, robust data on quality becomes available for primary care in Sweden. An important exception to this is the annual patient survey (discussed in Section 2.3) that provides rich data on user experience in primary care at county council and provider level.

Finally, although information flows to the registers are mainly electronic, there is no common IT infrastructure for data collection across quality registers, reporting methods differ between registers, and some registers are still paper-based. Thus, although quality registers are a valuable source of information about the quality of care and make Sweden an international exemplar in this respect, data submission and compilation processes could be streamlined to reduce the burden of data collection on clinical staff.

The IT environment, with stand-alone systems and a lack of inter-operability, does not adequately support co-ordination and the sharing of information and patient records across providers. As noted by Øvretveit et al., "clinical quality process and outcome data are needed for many different types of improvement, and current systems in Sweden and elsewhere do not support care co-ordination or allow data to be gathered to track how other changes might be impacting patient care" (Øvretveit et al., 2010). Another report also identified information systems and legal barriers to sharing patient information as barriers to co-operation by providers within and between health care and social services (Docteur and Coulter, 2012).

Increased transparency about quality and efficiency in health care is a priority for the Swedish Government. The publication since 2006 of the annual quality and efficiency reports, with population-based data for county councils, marked the beginning of this process. This is now being extended to the publication of data on provider performance to stimulate competition, improve responsiveness, support patient choice and provide accountability. Publication has also exposed variations in quality between regions and providers, and the scope for improvement. Transparency, reforms in primary care and the growing numbers of private providers have reinforced the need for quality data in primary care, so the climate is conducive for progress in this area.

There is no national system of accreditation or framework for quality assurance in primary care, which is primarily a responsibility of county councils

With its devolved system of administration, Sweden does not have a national, standardised system of accreditation for health care providers. In primary care, county councils define the accreditation criteria that incoming providers – including private providers – must meet before they become eligible for public funding.

A county council cannot prevent a practitioner from establishing a private practice; their regulatory power is restricted to controlling the public financing of private practitioners. The licensing of new private primary care providers eligible for public funding is based on compliance with stipulated conditions for accreditation, which focus on the minimum level of clinical competences required in primary care. The same requirements apply to both private and public providers. Since health care provision is decentralised to county councils, the conditions for accreditation vary across the country.

Quality assurance in primary care is also primarily a responsibility of the county councils. As with other health care providers, since 1 June 2013, the Health and Social Care Inspectorate plays an overarching inspection and supervisory role, but ongoing quality monitoring and assurance in primary care is largely undertaken by county councils. There are no national norms or standards against which the quality of primary care services is monitored, and how this function is performed varies locally. Data from the quality registers and locally available information from primary care providers are used by councils for monitoring quality. It is unclear how robust this process is, given the relative lack of data for primary care and that much of the focus of quality measurement and improvement is on inpatient and specialist care. Accreditation and public financing appear to be the main levers for quality assurance in primary care, with information playing a minimal role.

Clinical guidelines developed by the NBHW include recommendations for primary and community care. The county councils are responsible for implementing the guidelines, but the recommendations are not mandatory and the rigour with which they are implemented varies locally and between the recommendations. Adherence to the guidelines in primary care – as in other areas of health care – is monitored locally and some related indicators are reported in the publications by the Swedish Association of Local Authorities and Regions (SALAR) and the NBHW. No sanctions apply for non-compliance, although pay-for-performance incentives linked to evidence-based guidelines are used selectively and increasingly transparency is seen as a means of reducing variations in performance.

The government's assumption is that the primary care reforms introducing competition, plurality of providers, transparency and patient choice will drive improvement. There is some evidence supporting this view. An analysis of the association between the quality of GP practices in England and the degree of competition they face found that practices located close to other practices provide a higher quality of care than practices that lack local competitors (Pike, 2010). There is also evidence that patients choose practices offering higher quality of care (Santos et al., 2013). However, it is important for county councils to provide the necessary safeguards by having adequate governance and oversight arrangements in place for monitoring quality and care co-ordination, equity and value for money, and compliance with guidelines, and explicit rules for dealing with poorly performing providers. Policy options for a quality assurance system in primary care are discussed in Section 2.4

Quality assurance in primary care services is also an issue with home health care for people needing long-term care. With responsibility for home health moving from county councils to municipalities, the challenges will mount, as municipalities are smaller than county councils, and have fewer analytical skills and capacities for monitoring quality.

Primary care's role in care co-ordination needs greater clarification

In Sweden, the expectation by default has been that primary care will co-ordinate patient care, act as a guide, and take responsibility for health care in residential settings, including care homes for the elderly. However, no agency has formal responsibility overall for co-ordinating care for people accessing multiple care services across many care settings, including those provided separately by municipalities and county councils. Older people may receive health care from a variety of sources – county councils, municipalities or private providers – that do not always co-ordinate care with each other. The co-ordination role is sometimes undertaken by GPs or other primary staff, but patterns vary locally. Overall, care is better organised at the point of hospital discharge, but there is no national system for co-ordinating complex care needs once patients are in the community. Co-ordination between acute/elective/primary care/home care, and between specialist psychiatric care and primary care, is reportedly weak.

Assessments for social care are undertaken by municipalities, and not always co-ordinated with health care. Patients needing nursing in assisted living environments can sometimes lose contact with their GPs and some care homes are served by multiple GPs. A survey undertaken by the Swedish Medical Association (SMA) suggests that primary care doctors providing nursing home care have concerns about, for example, care continuity, medication risks, inability to follow up outcomes of care decisions, poor information flow between nursing homes and hospitals, and the lack of clarity about who is co-ordinating care.

As noted in a recent OECD report on long-term care, integration between health and social care and care co-ordination for the elderly and those with complex care needs remains a significant challenge in Sweden, driven by the division of responsibilities between medical care provided by county councils, and social care, nursing and rehabilitation provided by the municipalities (OECD, 2013). Decentralisation can create diffusion of responsibility, and the separate administrative and legislative frameworks for health and social care funding and management can compromise initiatives to promote integration (Wadmann et al., 2009). County councils and municipalities are required to sign agreements to co-operate on the provision of elderly and psychiatric care, but the effectiveness of such agreements in terms of leading to partnership working is unclear. In order to improve health care for older people, and co-ordination between social services and health care, the government intends to make one governing body responsible for all home health care for older people. It is in the process of transferring home health care from county councils to the municipalities, with a view to making all municipalities in Sweden responsible for home health care by 2014.

The reforms in primary care introducing choice and competition have improved access to primary care but could impact negatively on care co-ordination

National policies supporting the development of primary care have seen a significant expansion in capacity and provider numbers over the past decade, particularly in recent years with the introduction of reforms promoting competition and choice of primary care provider. Since January 2010, following a change in the Health and Medical Services Act, choice of primary care provider and freedom of entry for private providers that meet the accreditation standards set locally by county councils has become mandatory across Sweden. Several county councils had already implemented similar reforms prior to 2010, some offering choice of provider as early as the 1990s, although the entry of private providers is relatively recent. Over 200 private primary care providers have been established since the change in legislation, an increase of over 20%. Although public ownership of health centres is still the norm in many county councils, especially in rural and sparsely populated areas, the number of private providers increased significantly following the recent reforms. In some county councils they are significant players – in Stockholm, for example, about half of all primary care providers are private.

The reforms in primary care reflect the Swedish Government's wider agenda of using choice, competition and transparency of information about performance as a means of both empowering patients and improving the quality of health and social care services. Although there are no robust evaluations of the impact of the reforms, some positive impacts have been reported.

Despite the 2005 care guarantee of prompt access to primary care and a GP, supported by incentives to county councils since 2008 for meeting mandatory waiting targets, a shortage of primary care capacity and long waits has characterised the Swedish health care system for many years. The recent reforms are reported to have increased primary care capacity, reduced waiting times and improved access, including for low-income groups (Anell et al., 2012). The increase in primary care providers notwithstanding, relative shortages persist in rural areas because the expansion has occurred primarily in wealthier, urban and more densely populated areas. The reforms have also brought an increased focus on quality, efficiency and transparency, exemplified by the measurement and publication of information on performance to support patient choice (for example through the Open Comparisons website), and incentives to county councils and municipalities for quality improvement.

The government's expectation is that choice of provider, competition and transparency will enhance innovation within the sector. New forms of management, for example case and disease management programmes, are being developed in some county councils. But the extent to which the reforms will deliver on the goals of user-centered, well-co-ordinated care for older people and people with complex care needs is unclear.

Competition and choice mean that primary care's historical responsibility for population health in a geographically defined catchment area has been formally abandoned. This could potentially have negative consequences. For example: practice boundaries enable GPs to assess the health care needs of their registered patients so that local services can be planned most effectively; a geographically defined GP practice catchment population is useful for fostering join-up between other community health services (such as district nursing and mental health) and social care locally; and care, including emergency care and home visits, could become fragmented for patients registered out-of-area.

Feedback to the OECD team during its visit to Sweden was almost universally consistent that the reforms have not generally been conducive to improvements in care co-ordination, integration and continuity for elderly patients, people with complex care needs, stroke patients, those with cognitive impairment etc. (although thus far there is little hard evidence to this effect). It is also reported that for these groups of patients geographical proximity, continuity of interpersonal contacts with care professionals, and well-co-ordinated, integrated care are the priorities, and navigating the care system and exercising informed choice is a challenge (Docteur and Coulter, 2012). Finally, the dearth of information about quality in primary care reportedly makes it difficult to make an informed choice even when patients are able to exercise choice.

In 2012 the government launched an inquiry to examine the impact on quality, costs, efficiency, users and providers of the 2008 act relating to choice in public services. A review of the impact of the primary care reforms on access, quality, cost, care co-ordination and user experience would be timely and can inform future policy development in this area.

2.3. Quality and outcomes of primary care in Sweden

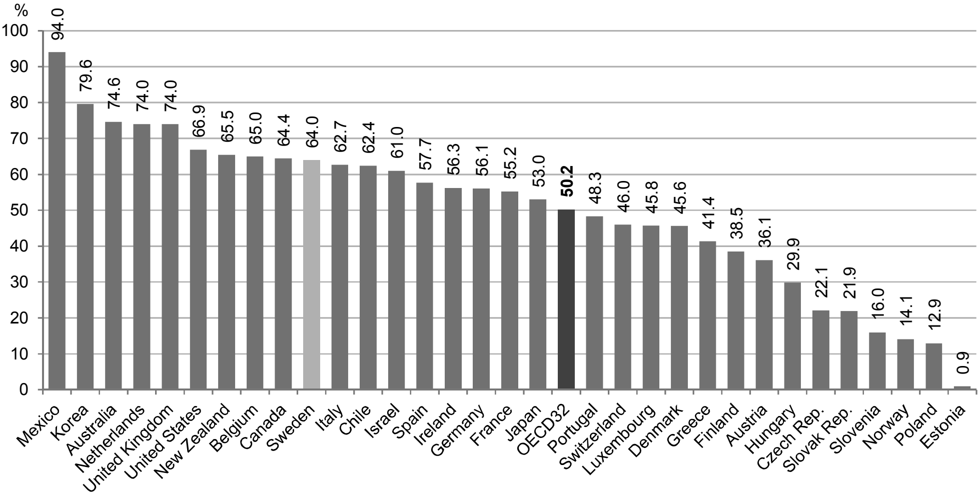
The contribution of primary care is reflected in the excellent health status indicators for Sweden

Health care, in which primary care is a key component, plays a key role in determining population health and the rate at which it improves. As shown in Chapter 1, Sweden compares very favourably with other countries on many health status indicators that are widely recognised as reflecting the quality of health care, amongst other determinants. For example, public health programmes and primary care play a key role in shaping health-related behaviours such as tobacco use, alcohol consumption and diet. In Sweden, smoking prevalence (13.1%) and alcohol consumption defined as litres per capita (7.4%) are among the lowest in the OECD (averages of 20.9% and 9.4% respectively), and self-reported obesity (11%) is also well below the OECD average (17.6%) (*OECD Health Statistics 2013*).

The performance of prevention programmes overall also compares well. Childhood immunisation rates are high relative to other countries and, at

2.1 per 1 000 live births, Sweden's infant mortality rate is among the lowest in the OECD (average of 4.1). Flu vaccination in the Swedish population aged 65+ (64%) is higher than the OECD average (50.2%), however, as shown in Figure 2.1, it is below the rates in some other countries.

Figure 2.1. Influenza vaccination coverage, population aged 65 and over, 2011 or nearest year

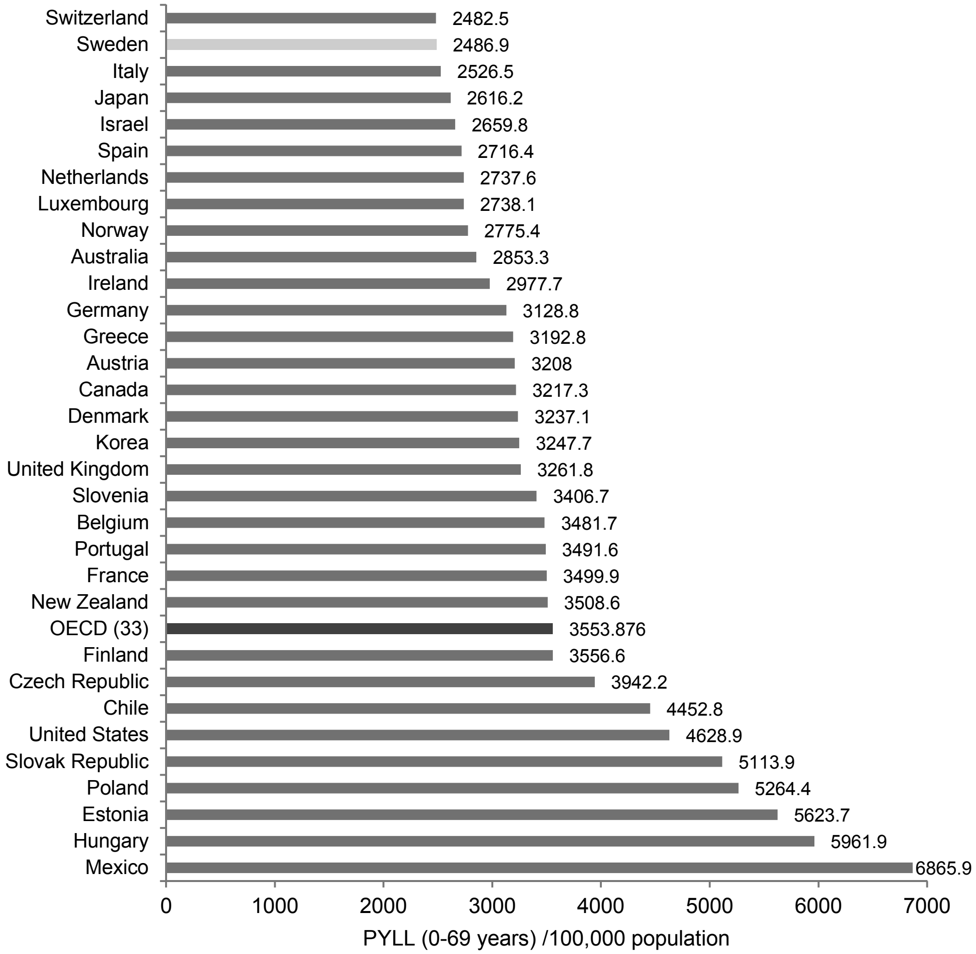


Source: OECD (2013), *Health at a Glance 2013 – OECD Indicators,* OECD Publishing, Paris http://dx.doi.org/ 10.1787/health_glance-2013-en.

As Figure 2.2 shows, premature mortality in Sweden, measured as potential years of life lost (PYLL) before age 70, is among the lowest in OECD countries. Mortality amenable to medical intervention is a significant contributor to premature mortality, accounting for about one-quarter of total mortality under age 75 in high-income countries; in international comparisons of amenable mortality, Sweden consistently ranks among the best (Nolte and McKee, 2011).

International comparisons also show that survival rates for lung, colorectal, breast and ovarian cancers are generally higher in Sweden, Australia and Canada than in Norway, Denmark and the United Kingdom (Coleman et al., 2011). Screening and 5 year relative survival rates for cervical cancer, and survival rates for breast cancer, are among the highest in the OECD, although Sweden's relative survival rate for cervical cancer (68.4%) is lower than the rate for Norway (71.4%) and Korea (76.8%).

Figure 2.2. Potential years of life lost (PYLL), 0-69 years, males and females, 2010 or nearest year

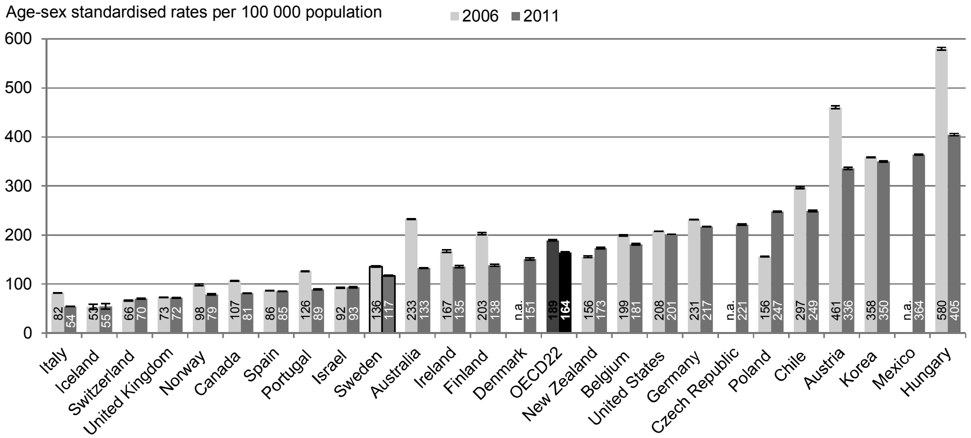


Source: OECD (2011), *Health at a Glance 2011 – OECD Indicators,* OECD Publishing, Paris, http://dx.doi.org/ 10.1787/health_glance-2011-en.

Hospital admission rates for conditions considered to be manageable in primary care show a more mixed picture

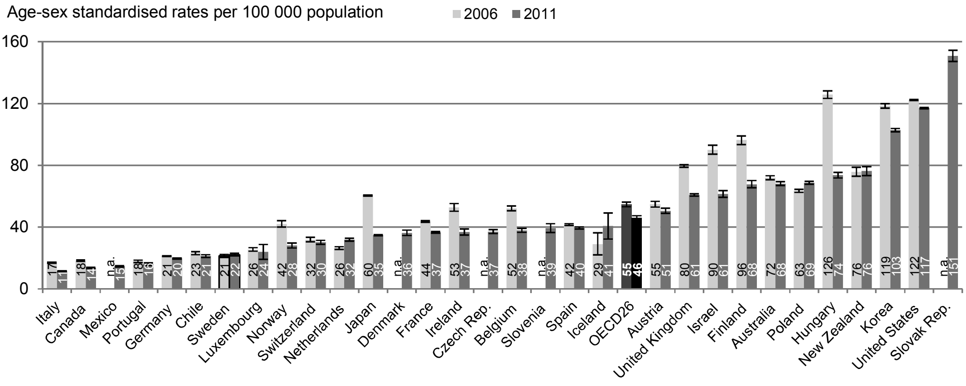
Some hospital admissions and readmissions are potentially preventable through better management and care co-ordination in primary care, and are associated with sub-optimal patient outcomes and avoidable costs of care. For example, chronic conditions like asthma and chronic obstructive pulmonary disease (COPD) are manageable through appropriate interventions in primary care, which can reduce exacerbation and costly hospitalisation. Hospital admission rates for such conditions are widely used as a proxy for primary care quality, as high rates may point to structural constraints such as an inadequate supply of primary care doctors, or poor care continuity and care co-ordination. As Figure 2.4 shows, Sweden's admission rate for asthma (22.2 per 100 000 population) is among the lowest in the OECD (average 45.8). Its admission rate for COPD (168.8 per 100 000 population) is also lower than the OECD average (203), although higher than for some other countries (e.g. Portugal 70.5, France) (see Figure 2.5). Sweden compares well with other OECD countries on diabetes hospital admission in adults with a reported age-sex standardised rate of 116.9 (see Figure 2.3).

Figure 2.3. Diabetes hospital admission in adults, 2006 and 2011 or nearest year



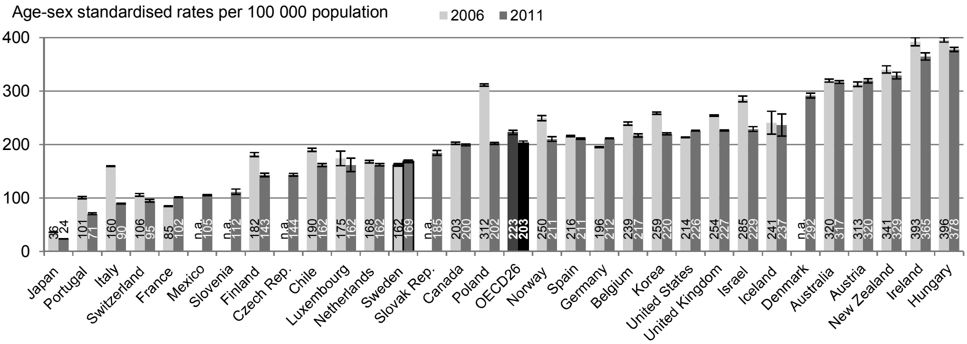
Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Figure 2.4. Asthma hospital admission in adults, 2006 and 2011 or nearest year



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Figure 2.5. COPD hospital admission in adults, 2006 and 2011 or nearest year



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Regional variations in the quality of primary care show the potential for improvement including in secondary prevention

Sweden's very favourable standing in international comparisons of health status and health care quality masks some variations in the quality of primary care between regions and population sub-groups. These are described in the annual reports on quality and efficiency in Swedish health care, the aim of which is to improve quality overall by reducing such variations where they are avoidable (Swedish National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, 2011;

Swedish National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, 2013). Some regional variations are inevitable and unavoidable, reflecting differences in, for example, risk factors, disease prevalence and case-mix. Although most indicators have improved over time, the data show the potential for improvements in primary care, including through reducing unwarranted regional variations.

Illustrations of such variations in the latest report published in 2013 are given below. The report comes with a caveat about data quality as participation rates in the quality registers, from which many of the indicators are derived, vary. It also notes that internationally comparable data are not generally available for these indicators.

In terms of prevention, Sweden compares favourably with other countries across a range of indicators. For example, MMR vaccination rates are high and show little regional variation at 97-98% in all counties. Sweden's cervical cancer screening rate compares favourably with other OECD countries, however, the national average of 80% conceals county level variations ranging between 65-92%, with counties with low participation rates generally having a higher incidence of cervical cancer than those with high participation rates.

The Swedish NBHW published new diabetes care guidelines in 2010. The indicators used to monitor the quality of diabetes care are consistent with the recommendations of the guidelines. Data from the national diabetes quality register, covering both primary and hospital care, are used for reporting purposes. Although overall participation in the register has improved in recent years to an overall rate of 85%, coverage is much better in hospitals than in primary care and there are wide variations between counties. The data show that diabetes is under-treated and there is a need for improved compliance with the guidelines and follow-up of treatment. For example:

- In 2011 about half of diabetes patients aged under 80 years met the HbA1C goal, 78% were below the upper limit, and 9% showed very poor blood glucose control. The average HbA1c for primary care patients has not changed in recent years and improvements appear unlikely unless clinical practice is modified.
- The mean blood pressure level in diabetic patients has declined steadily in recent years. The proportion reaching the blood pressure goal of <130/80 mm Hg was 23% in 2011, with a two-fold variation between counties. The proportion with blood pressure lower than 140/80 mm Hg was about 61%. The results point to under-treatment and the potential for improvement in all regions.

- The use of lipid lowering therapies has increased over the years, leading to improved lipid control. However, there is scope for improvement, as only 46% of diabetic patients under age 80 achieved the LDL cholesterol goal, with county level variations of between 36-58%.

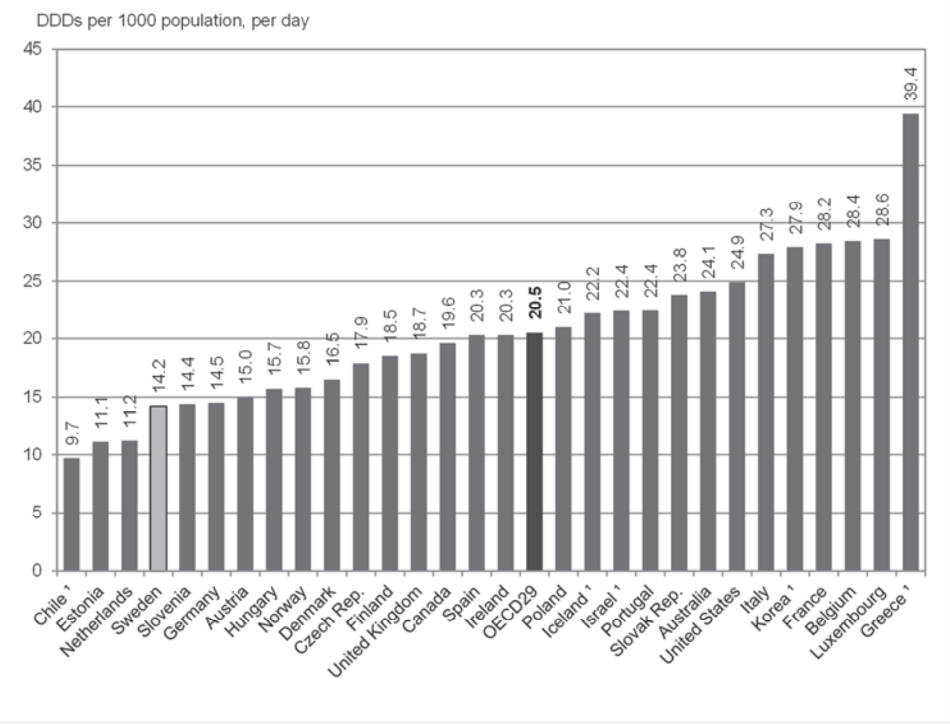
Cardiovascular disease (CVD) is the commonest cause of death in Sweden. On several indicators for stroke and acute myocardial infarction, treatment in line with guidelines and outcomes have improved significantly. However, there is potential for improvement in secondary prevention for CVD in primary care. For example, about 8% of 80 000 first episode stroke patients in 2006-10 were readmitted for stroke within 365 days of their initial episode, with county readmission rates varying between 5-10%. Hospital readmissions among stroke patients provide an indication of the efficacy of secondary prevention after stroke. Subject to contra-indications, anticoagulant therapy for stroke patients with atrial fibrillation is a high-priority therapy in the national stroke guidelines to prevent a recurrence; in 2009-10 two-thirds (67%) of such patients were given anticoagulant therapy in the 12-18 months after discharge from hospital, with large regional variations. Likewise, treatment with statins for secondary prevention after cerebral infarction is recommended in the guidelines; 71% of patients were prescribed statins within 12-18 months after discharge, with most counties needing to be more compliant with the guidelines.

The Swedish Council on Technology Assessment in Health Care and the Medical Products Agency have shown that preventive drug therapy (with bisphosphonates or hormones) for older people with osteoporosis and fractures reduces the risk of additional fractures. Thus, it is important to assess whether osteoporosis is diagnosed and treated after older women receive care for a fracture. In 2009-11, 14% of women nationally had been treated, with inter-county variations of between 7-22%, suggesting that not all care providers and county councils are applying the national guidelines. The Senior Alert Quality Register can be a useful basis for targeting preventive interventions.

Some of the observed regional variations in prescribing patterns may be unwarranted, with potential for improvements in line with evidence on good practice. For example, long-term use of benzodiazepines, prescribed most often by GPs, and also by psychiatrists, can cause adverse effects and they should not be prescribed routinely. Use of benzodiazepines varied by almost 75% between counties in 2011; it is unclear whether this is due to differences in clinical practice or other factors. Similarly, rates of poly-pharmacy among older people vary from 10-14% between counties, and the proportion of older people using three or more psycho-pharmacological drugs concurrently varies almost two-fold.

On the other hand, trends in antibiotics prescribing are encouraging. Consumption of antibiotics is correlated with the spread of resistant bacterial strains, hence there is an international drive to limit their use. Antibiotics prescribing in Sweden has declined over time, although the variation in prescribing rates between counties in 2011 was about 40%. Nonetheless, as shown in Figure 2.6, Sweden's rate of overall antibiotic prescribing in primary care is among the lowest in the OECD; in common with other Nordic countries, it also has among the lowest prescribing rates for broad spectrum antibiotics.

Figure 2.6. Overall volume of antibiotics prescribed, 2010 or nearest year



1. Data refer to all sectors (not only primary care).

Source: OECD Health Statistics 2013, http://dx.doi.org/10.1787/health-data-en; IMS for United States.

Hospital admissions for selected acute and chronic conditions that are potentially avoidable through timely and effective primary and community care, using the Swedish definition, declined between 2006 and 2011, but they still account for about a million bed days annually. Regional variations of almost 40% show the potential for improvements in primary care. Avoidable hospital admission rates in 2011 for medical care for people previously (2006-10) admitted with a psychiatric diagnosis are four times higher than among the general population. While this reflects international evidence about higher physical morbidity among people with mental health problems, it also illustrates the potential for improved physical care for this group of patients in primary care.

Deaths that are potentially avoidable through early detection and treatment, one of the NBHW's indicators based on diagnoses of diabetes, appendicitis, stroke, gallstone disease and cervical cancer, show a greater than 50% variation between counties. Although mortality has declined for all groups over the past decade, significant differences by educational status persist.

Equitable, universal and needs-based access to health care is legally enshrined in Sweden. While Sweden has among the best health status indicators internationally, the publication of performance data shows socio-economic inequalities in the quality of care. Those with the least education have higher mortality rates and a greater incidence of avoidable hospitalisation. For example, survival rates for breast cancer are lower in women with low education, and rates of potentially avoidable hospital admission and amenable mortality are about double among people with lower educational status compared to those with higher education. This is illustrative of other differences in health status and outcomes between socio-economic groups. A strategy for managing geographical and socio-economic health inequalities is under development by the government.

Overall, Swedish people are satisfied with the quality of primary care but access to services and care co-ordination need to improve

Data on perceptions among the general population about the availability and reliability of health care services are available from the annual health care survey introduced in 2001. This is supplemented by data on patients' experience of using primary care services from the national patient survey programme, introduced in 2009 and co-ordinated by SALAR. These surveys provide valuable benchmarking data on feedback from users of primary care services, down to county council and practice level. These data can inform quality improvement initiatives in primary care and monitoring of trends over time.

Sweden's population-based surveys show a higher level of confidence in hospitals than in primary care. In 2011, 64% of the population reported having confidence in primary care, varying from 59-75% between counties, compared with 71% reporting they had confidence in their hospitals

(Swedish National Board of Health and Welfare and Swedish Association of Local Authorities and Regions, 2013). While 12% of respondents said they had little confidence in primary care, the corresponding figure for hospital care was 7%.

However, satisfaction levels were significantly more positive among users of primary care users, and were on a par with responses from users of specialist and hospital care. In the 2011 survey of primary care patients, 90% of respondents said they were treated with respect and consideration by staff, 78% said they had received sufficient information about their condition, and 78% said they had participated in care and treatment decisions. Variations between counties were relatively small, but variations at clinic level are larger.

Sweden compares well in international comparisons of user experience, although not in all areas, notably access. In an industry-sponsored pan-European survey covering 42 indicators across five domains of the performance of national health care systems from a user/consumer viewpoint, Sweden had the sixth highest ranking overall among 34 countries (Björnberg, 2012). While Sweden performed well in many areas, outstandingly so on health outcomes, it compared less favourably on access, including same day access to a primary care doctor. In a 2012 survey of primary care doctors across 11 countries, the proportion saying all patients could get a same or next day appointment was significantly lower in Sweden (28%) than in several countries (e.g. France 86%, Switzerland 62%, Netherlands 61%) (Commonwealth Fund, 2012). The proportion responding that practices had after-hours arrangements for patients was also lower in Sweden (67%) than, for example, in the United Kingdom, Netherlands and New Zealand (90% or higher).

Given the historical problem of long waits, Sweden has national care guarantees with specific waiting time targets. For primary care, the targets are that a patient should be able to contact primary care immediately and get an appointment with a primary care doctor within seven days. Official data for March 2012 show that the seven day target was met for 93% of patients, with regional variations of 83-98%, although patient-reported perceptions of availability are lower at about 81%. Access to primary care has improved significantly over time, and is reportedly improving further with the reforms underway, but waits for both primary and specialist care are still an issue in the Swedish health care system.

Feedback from primary care doctors and patients indicates that care co-ordination in Sweden lags behind other countries. In a 2012 survey of primary care doctors across 11 countries, the proportion responding that the practice uses nurse case managers or navigators for patients with serious chronic conditions was second lowest in Sweden at 41%, compared with 78% in the United Kingdom and 73% in Netherlands (Commonwealth Fund, 2012). The proportion saying the primary care doctor receives needed information to manage the patient within 48 hours of discharge from hospital was also among the lowest in Sweden (21% compared with 67% in Germany for example). A 2011 survey across 11 countries of adults with complex health care needs found longer waiting times in Sweden, difficulty in accessing after-hours care and higher use of emergency services, and patient engagement in care management for chronic conditions was weakest in Sweden (Schoen and Osborn, 2011). However, the proportion reporting cost as a barrier to access was lowest in Sweden and the United Kingdom. The study concluded that patients who are engaged in their own health care receive higher-quality care, experience fewer medical errors, and have more positive views of the health system.

A report on patient-centeredness in Swedish health care reported that, while Sweden has made good progress in strengthening legislation pertaining to information and education for patients, gaps and regional variations are evident in these areas, and the health care system is inadequately responsive to patients' needs (Docteur and Coulter, 2012). For instance, patient surveys in both primary care and inpatient specialised care show that doctors sometimes fail to tell patients about the side effects of their medicines and warning-signs about their condition to watch out for. Based both on international comparisons and domestic patient surveys, the report identified inadequate care co-ordination as a weakness in Sweden's health care system, particularly in relation to specific groups such as psychiatric patients and the sickest elderly. The barriers to co-ordinated care identified are reimbursement systems, vertical organisation of health care that makes it difficult to co-ordinate care processes horizontally, and lack of assistance for patients in negotiating their way through services involving multiple providers, as in care for patients with complex conditions or post-hospital rehabilitation care. Taken together, these findings support other evidence that primary care's role in care co-ordination in Sweden needs to be strengthened.

2.4. Maximising primary care's contribution to high quality, co-ordinated care in Sweden

The role of primary care in improving quality and reducing the disease burden has potential for improvement

Primary care is regarded as uniquely well placed not just to provide medical care, but also to promote the health and wellbeing of the practice population (Thorlby, 2013; Goodwin et al., 2011). International evidence also shows that health care systems with a stronger primary care focus are likely to deliver better chronic care management. With its wide population coverage, highly accessed services, and strong generalist tradition, primary care in Sweden is uniquely well placed to capitalise on its knowledge of patients and their local contexts, gained from repeat contacts over extended periods of time. Exploiting this potential in a more proactive approach to improving population health and wellbeing can help to contain the rising rates of chronic disease in an ageing population. These attributes of Sweden's well-developed primary care sector also put it in a strong position to improve the management of chronic disease and its sequelae.

Sweden's highly skilled primary care sector has contributed to impressive improvements in quality and outcomes, and to shifting the use of services away from hospital care to primary and community services. There is potential for further improvement. Regional variations in performance and other evidence suggest that there is scope for deploying the skill base of primary care teams more effectively to improve quality, address primary and secondary prevention, and reduce the use of hospital and specialist care further.

Hypertension, tobacco, alcohol misuse, obesity and low physical activity are the leading risk factors for illness and disability in western Europe but are amenable to intervention at national and local levels, including through health services. Although the primary prevention role of Swedish primary care encompasses advice and support to patients on lifestyle habits, it is unclear how effective these interventions are. The NBHW acknowledges that the recommendations add to cost and workloads, in primary care and there is a need for skills development and training. Furthermore, GPs may consider that population health is not their responsibility and may be reluctant to take on the added workload of counselling on lifestyle issues. While Sweden's immunisation and screening rates are high and compare well with EU countries, primary prevention, health education, case-finding and early diagnosis are key roles for primary care.

Enhancing primary care's role in primary prevention requires more proactive deployment of staff for delivering these functions and better use of data and risk stratification tools. Policy makers may also want to consider adapting payment systems and contracts to encourage a focus on population health, including through strategic alliances between primary care and other local agencies to tackle risk factors for ill health.

There is potential for improvement in primary care's management of chronic disease and secondary prevention, which could improve patient outcomes and reduce care costs. A study of the use of evidence-based practices and computer systems for managing chronic illness in Swedish primary health care found variations in and under-use of evidence-based care management practices and of IT for managing asthma, heart disease, diabetes and depression (Øvretveit et al., 2008). Other research also shows that adherence to guidelines and treatment for asthma shows room for improvement (Ingemansson et al., 2012; Weidinger et al., 2009). The need for better compliance with guidelines and structured programmes for COPD care has been reported, and that larger centres and use of specialist nurses offer a better infrastructure for providing guideline-defined COPD care (Thorn et al, 2008, Löfdahl et al., 2010). Regional data for Sweden shows variations in the quality of primary care follow-up and secondary prevention for stroke patients, with anecdotal evidence suggesting stroke care on discharge from hospital can be fragmented. As noted in the chapter on stroke and hip fracture, secondary prevention in these areas can be strengthened. Guidelines for CVD and hypertension need to be better implemented, and management of these conditions improved (Carlsson et al., 2013; Neiburg and Kahan, 2010; Midlöv et al., 2008). There is evidence of under-provision of drug treatment for several major disease areas.

Data from SWEDEHEART show that only 17% of heart disease patients managed by hospital outpatient clinics achieve all four goals of blood pressure and cholesterol control, smoking cessation and participation in an exercise programme (RIKS-HIA, 2012). Although a very positive finding is that drug treatment regimens are largely in line with current guidelines, up to 50% of patients do not reach blood pressure and cholesterol targets one year after a myocardial infarction. SWEDEHEART notes that there has been little change in these secondary prevention measures in recent years, showing potential for improvement in the management of myocardial infarction patients. Given the poor data linkage with primary care, it is unclear how primary care is performing in secondary prevention of heart disease, and whether the impressive quality improvements seen in secondary care are matched in primary care.

Mental health is another area with potential for improvement. About 15% of men and 20% of women in Sweden rate their mental wellbeing as impaired in national surveys using GHQ-12, a validated instrument used internationally for measuring mental wellbeing, early detection and treatment. Primary care is generally the first point of contact, and is responsible for minor mental health problems and onward referrals to specialist care for those with serious mental illness. High quality primary care for mental health problems is especially important in rural areas where access to specialist services may be difficult. The prevalence of mental health problems is common, with one in three patients in primary care showing symptoms of depression, anxiety or alcohol problems (Nordström and Bodlund, 2008). Early identification, intervention and treatment in primary care is therefore important. GPs play a crucial role in detecting and treating these common mental disorders, which often go under-diagnosed and untreated because many patients present with somatic symptoms (Wallerblad et al., 2012). Diagnosis and treatment of these disorders can be a challenge for GPs, and misclassifications (false positives and false negatives) are not uncommon. A survey in the four Scandinavian countries showed that misclassifications of major depressive episode were common in primary care patients, with GPs recognising the condition in 56-75% of cases (Ostergaard et al., 2010). Physical health care for people with mental health problems, access to psychological therapies and the interface with specialist mental health services are also areas for improvement in primary care.

The government's initiative for improving health and care services for the most fragile elderly, to which it has allocated EUR 500 million for 2011-14, includes dementia as one of the priority areas. The initiative includes pay-for-performance incentives to improve case-finding, early diagnosis and assessment for people with dementia. Although dementia care is a priority area supported by several government initiatives, it is recognised that the role of primary care in these areas needs to be strengthened and compliance with national guidelines can be improved. Dementia prevalence in Sweden (6.3% among people aged 60 years and over in 2009) is among the highest in the European Union (average 5.5%). Data from the dementia quality register show that the national dementia guideline goal of a diagnosis in primary care within 30 days is currently not met in any of the provinces, about 50% of patients in primary care undergo basic work up (somatic, functional, cognitive, psychological assessment, CT scan, etc.), 20% of dementia patients in nursing homes are treated with anti-psychotics, and quality of dementia care generally falls short of the seven quality indicators identified by the NBHW. Improvements in diagnosis, support and treatment for dementia could improve quality of life for patients and save public funds in the long term by reducing the need for care home places and unnecessary hospital admissions. An obstacle to early diagnosis may be GPs' capabilities in dementia care. Surveys in the United Kingdom suggest that many GPs feel they lack the training, confidence and time to deal with dementia.

The government offers incentive payments to county councils and municipalities for reducing avoidable admissions and readmissions within 30 days among people aged 65+. Although performance fell short of the goal of reducing readmissions by 10% within a year, most councils achieved reductions of 2-3% and some councils have moved to a proactive risk stratification approach to identify elderly patient with high care needs. Research suggests that a) only about a quarter of readmissions are deemed preventable (Joynt and Jha, 2012), which could be why reducing readmissions proves so intractable in many countries, and b) readmissions are associated with admission rates, so incentivising reductions in hospital use generally may be more effective as a means of reducing readmissions (Epstein et al., 2011). This again points to primary care's role in effective prevention.

In summary, there is potential for primary care in Sweden to play a more proactive role in primary and secondary prevention, and the management of chronic disease, mental illness and multi-morbidities. Potential levers can be contractual mechanisms between county councils, municipalities and primary care requiring compliance with guidelines, supported by clearer standards and targeted incentives for primary and secondary prevention. Sweden's skilled primary care workforce has the potential for an increased role for nurses and allied health personnel, especially in managing patients with chronic disease. Improved data collection and greater use of quality indicators in primary care will also support progress towards the goals outlined. Finally, the policy environment should promote primary care's role in improving population health.

Enhancing the role of primary care in care co-ordination

The reforms in primary care should actively promote care continuity and co-ordination

Care continuity and care co-ordination is important for people with higher care needs, such as those with chronic conditions and older people, who often need both medical and social care and long-term follow-up. Since patients in many countries enter the health care system via primary care, and retain contact with it through their care journey, the role of primary care is widely seen as critical to improving care co-ordination (Masseria et al., 2009). A systematic review to identify the core dimensions of primary care noted that continuity and co-ordination of care are among the ten elements of primary care as a multi-dimensional system, contributing to improved quality, outcomes, patient satisfaction and efficiency (Kringos et al., 2010). Countries with a gate-keeping model of primary care are better positioned to provide care continuity and co-ordination.

As primary care is generally the point of entry into Sweden's health care system, organised in multidisciplinary teams and involved in post-discharge planning, and satisfaction levels with it are high, it is potentially well placed to play a strong, proactive role in care co-ordination. The evidence cited in this chapter shows that care co-ordination is a relative weakness in Sweden's otherwise strong health and social care system. Although many countries struggle to provide well co-ordinated, patient-centered care, Sweden compares relatively unfavourably on international surveys of patients and doctors in these areas. It is important therefore that the reforms are structured to foster co-ordination rather than fragment care further.

The reforms in Sweden focus on user choice, competition and a diversity of providers. Such policies do not of themselves facilitate co-ordination, and can present real or perceived barriers to integration. Choice and competition in primary care, and the resulting loss of a geographical responsibility for population health, have the potential to exacerbate fragmentation of care and impede the ability of local agencies to work together to provide seamless health and social care in the most cost-effective way – especially in urban areas with a multiplicity of providers. The risks of fragmentation and poor care co-ordination are greatest for older people, complex and frail patients, and people with mental health problems; these are also the groups least able to navigate the system and exercise informed choice, hence they can be disenfranchised from the reform process.

However, these policies need not pose insurmountable barriers to better care co-ordination so long as competition and a plurality of providers do not mitigate against collaborative partnerships and integration, and are not perceived to be counter to these goals. Many health care systems share the Swedish goal of empowering patients to exercise informed choice, and there is evidence that geographical monopolies can stifle innovation and that competition in primary care drives quality. An empirical analysis of the relationship between the quality of GP practices in England and the degree of competition they face shows that practices located close to other practices provide a higher quality of care than practices that lack competitors (Pike, 2010). Moreover, recent research shows that patients are more likely to choose practices which earned more quality points under the Quality and Outcomes Framework (QOF) pay-for-performance scheme; a necessary condition for greater competition to improve quality is that patients' choice of practice is influenced by practice quality (Santos et al., 2013).

Polarised distinctions between the merits and flaws of competition and integration no longer hold, and many health care systems subscribe to the importance and place of both in delivering high quality, cost-effective care. Several commentators note that integrated health care and choice can be reconciled if patients are able to choose between integrated health care arrangements and networks, and not between narrowly defined components of service (Ahgren, 2010; Ham, 2012; Hawkins, 2011; Ham and Curry, 2010). The competition and privatisation reforms can be designed to promote care continuity and co-ordination, including through appropriate payment mechanisms, and these principles should be embedded in the regulation of how these policies are implemented in practice. Strategies for progress towards these goals are discussed below.

Sweden's model of primary care lends itself to better care co-ordination

Sweden's model of large, multidisciplinary primary care teams and specialist nurses is conducive to collaboration and greater use of practice staff than health care systems with a preponderance of small or solo practices, as in Denmark. Evidence suggests that co-location in multidisciplinary health centres facilitates collaboration and integration, and ensures more efficient use of resources and competencies (Reed et al., 2005). Multidisciplinary practice teams, with clinical, IT and other support infrastructures, are able to provide a wider range of services for meeting chronic care needs on a co-ordinated basis (Goodwin et al., 2011), and are better able to implement the chronic care model and other models of integrated care than smaller practices (Hofmarcher et al., 2007; Lieshout et al., 2011; Friedberg et al., 2009; Wensing et al., 2006). Several national studies of the influence of practice size on care processes and outcomes show that larger practices perform better in terms of the range and quality of services and safety management (Wensing et al., 2006; Gaal et al., 2010; Friedberg et al., 2009; Campbell et al., 2001), although smaller practices are associated with higher patient satisfaction (Glenngard, 2012).

Two widely accepted frameworks for the organisation of chronic care and prevention are the chronic care model (CCM) and the patient-centered medical home (PCMH) (Lieshout et al., 2011). The CCM seeks to co-ordinate activities within primary care by fostering productive interactions between trained proactive care teams and well-informed, motivated patients. There is evidence from the United States and Europe that the CCM improves patient care and health outcomes for patients with chronic illnesses (Coleman et al., 2009). The PCMH model combines traditional primary care core values such as continuity, co-ordination, and comprehensiveness, and is predicated on patients having enhanced access to a personal physician.

The 2011 Commonwealth Fund survey of patients with complex care needs found that care is often poorly co-ordinated in the 11 countries surveyed (Schoen et al., 2011). However, adults seen at primary practices with the attributes of a PCMH – where clinicians are accessible, know patients' medical history, and help co-ordinate care – rated their care higher and were less likely to experience co-ordination gaps or report medical errors. The conclusion supports the need for redesigning primary care, developing care teams accountable across sites of care, and managing transitions well. To support this evolution, general practice needs to see itself as the hub of a wider system of care, with responsibility for co-ordination and signposting, including to services beyond health care

(Goodwin et al., 2011). Primary care is at the centre of the care system in Sweden, and well positioned and qualified to take on such a role.

Frameworks such as CCM and PCMH can have locally distinctive applications, and lend themselves to adaptation in Sweden's devolved health care system. Sweden's decentralisation form of government means that local organisations have the levers to innovate and promote collaboration and co-ordination, for example, through economic incentives and regulation. Disease management programmes can also improve communication between providers and benefit patients. New forms of management, for example case and disease management programmes, are already being developed in some Swedish county councils. They are growing in importance across many countries, although their disease-specific focus does not address the issue of multi-morbidities.

Moving to a gate-keeping role for primary care, with universal registration with a practice, would appear to be a necessary pre-requisite if primary care in Sweden is to undertake the lead responsibility for care co-ordination. Without this, it is not practical for primary care to have a comprehensive over-view of the care received by individual patients, and to ensure that all patients have this cover. It will also better enable primary care staff to monitor patients with chronic or complex conditions, make referrals as needed, and co-ordinate their care across different services. The SMA notes that the weak interface between community and home-based care results in some patients being rushed to hospital needlessly, and should be addressed via defined catchment areas for primary care and the registration of care home residents with a named doctor, nurse, specialist or practice responsible for providing continuous, holistic and proactive care.

Improving primary care's role in care co-ordination requires strategies for tackling the barriers to co-ordination and promoting new ways of working

Strategies for improving care co-ordination need to address the potential obstacles and create an environment that fosters different ways of working. This must start with a clear articulation of Sweden's vision for the future of its primary care system, which defines the roles envisaged for primary care, the workforce complement and skills needed to deliver those functions, and the organisational developments needed to achieve identified goals. The vision should define also the role of primary care in co-ordinating care in a modern Swedish health care system. An example is the recent report by United Kingdom's Royal College of General Practitioners, which outlines the model of general practice and roles of GPs and other primary care staff envisaged for 2022 (Royal College of General Practitioners, 2013). The vision is for a comprehensive, accessible, high quality service, provided by a skilled, resilient, adaptable, multidisciplinary workforce that delivers health promotion and disease prevention strategies to local populations, manages multi-morbidity and co-ordinates complex care across boundaries. GPs in 2022 are seen as the "expert generalists", needing to have an understanding of generalist care and also high-level skills to manage complex patients with chronic medical conditions and to deal with poly-pharmacy. It will be important for such a national vision for primary care in Sweden to be shared by SALAR, county councils, municipalities and leaders in primary care.

A common theme in the literature is that improving care co-ordination and integration also requires leadership, change management capacity, cultural change, and a breaking down of occupational barriers and fear of loss of professional autonomy. It requires action to ensure that the policy environment, regulation and governance structures, reimbursement and inventive systems, and information infrastructure are conducive to change, and there are effective dissemination routes for the spread of good practice. Integrated, community-based care also requires investment in primary care.

Investing in primary care

Policies oriented towards a shift of demand from hospital care to ambulatory care increase the pressures on primary care. The Swedish Government is investing EUR 500 million during 2011-14 to improve health and social care for the most fragile elderly, including for strengthening incentives to councils and municipalities for achieving pre-specified goals in preventive, dementia and palliative care, better use of medication and better care co-ordination. However, Swedish data show that primary care costs per year of age increase minimally into older ages compared with inpatient costs, which may indicate under-provision for primary care relative to secondary care. An appropriate balance of resources between ambulatory care and inpatient care is important for ensuring that the primary care sector is able to manage and co-ordinate the complex care needs of people with chronic conditions and co-morbidities. Redirecting resources to primary care can strengthen access to preventive care, improve chronic disease management and care co-ordination services, and reduce or delay the complications of chronic disease. Investment in primary and community care services is therefore a pre-requisite for general practice to operate on scale as the hub of a wider system of care that takes responsibility for care co-ordination and sign-posting people through the health and social care system.

Payment systems

Reimbursement systems can be an obstacle to care continuity and co-ordination. Fee-for-service and capitation funding models do little to promote quality of care, partnership working and care co-ordination for people with long-term conditions or the frail elderly. The Swedish Government gives grants to promote co-ordination, but a comparison of co-ordination between primary and secondary health care in Denmark and Sweden shows that in both countries economic incentives for collaboration are weak, and use of sanctions as a regulatory means is lacking (Wadmann et al., 2009).

Provider contracts should be formulated to provide incentives for better co-ordination, specifically, to include services that enhance care co-ordination, and reimbursement arrangements need to align incentives appropriately. An increasing number of countries are offering financial incentives for providers to co-ordinate care, with explicit payments for care co-ordination at primary care level (Masseria et al., 2009). Bundled provider payment currencies are also increasingly being adopted. An OECD review showed that countries have begun to restructure incentives for ambulatory care providers, or developed other incentives, accompanied by regulatory changes, to break down barriers between sectors and stimulate co-operation across providers (Hofmarcher et al., 2007). The OECD noted that the difficulties faced by many countries in co-ordinating care across interfaces may in part reflect the split responsibility for health and for long-term care across government departments, and it requires broader, system-wide approaches to improve care co-ordination.

Integrating care

A systematic review of the research literature on health systems integration identified ten principles of integration (Suter et al., 2009). They resonate with messages in a recent report by The King’s Fund and Nuffield Trust for the Department of Health in England, designed to support the development of the Department’s national strategy on integrated care in the context of the NHS reforms (Goodwin et al., 2012). This report identifies the barriers to integrated care, how they can be addressed, and the key enabling elements of a framework for integrating health and social care, with messages that are relevant in the Swedish context. These include: defining a national narrative for integrated care, allowing time for local innovative models to embed, aligning financial incentives and tariffs, data sharing, developing accountability and governance arrangements that encourage integrated care, allowing a nuanced interpretation of competition and patient choice, supporting leadership and organisational development, and evaluating the impact of integrated care. Importantly, policies on regulation and competition need to stimulate integrated care, which requires clarity for all stakeholders about how the rules around competition and integration will be interpreted in practice.

Delivering high quality, well-co-ordinated care requires an environment that fosters the development of new models of shared care between providers that integrate services across boundaries, including in the community, hospitals, and care and well-being services (Goodwin et al., 2011). The evolution of such models does not need to be standardised, and can be tailored to the specific health needs of local communities. A review of six initiatives[1] considered successful in increasing integration found that, although they spanned five countries and differed in their design and payment systems, a common denominator was the high degree of bundling in their payment systems, with a single budget used to pay for multiple components of a person's health and social care (Hagbjer, 2012). Several initiatives also integrated the delivery of health and social care in one organisation. The studied initiatives suggest that it is possible to combine such models of care with user choice between different providers.

Similarly, a report by the NHS Confederation on the principles, drivers and enablers for integrated notes that, while there are no consistent approaches to integration across the United Kingdom, the majority of integrated care pilots involved integration of practitioners working in different organisations and examples of horizontal integration, such as that between community services and social care (NHS Confederation, 2012). The notable example of Torbay Care Trust illustrates the impact of integrated health and social care on reducing use of secondary care and improving user experience (Thistlethwaite, 2011). Similarly, a study by the Commonwealth Fund of care management programmes that spanned care settings and engaged interdisciplinary teams across the continuum of care found that multifaceted, boundary-spanning approaches were associated with reduced hospital use and readmissions (McCarthy et al., 2013). In contrast, isolated interventions are typically not effective at reducing hospital readmissions.

These models contrast with the Swedish system, which does not generally bundle payments for different types of care, nor is there much organisational integration of care. An exception is the structural integration of health and social care in the TioHundra project in Norrtalje municipality, combining purchasing, service provision and political governance, with comprehensive responsibility for health and social care services for a defined population (Øvretveit et al., 2010). Such integrated care provision is supported by older service users and consistent with Sweden's goal of providing user-centered care. Increased competition and the emergence of new providers now highlight the need for strengthening integration of the commissioning function, to support integration of care activities between providers (Sjogren and Ahblom, 2012).

The Norrtalje example illustrates the potential in Sweden for developing innovative models which could take a variety of forms to suit local organisations and circumstances e.g. transfers of responsibility for health and social care between county councils and municipalities, joint commissioning by county councils and municipalities, use of incentives and sanctions, integration of different types of care within the same organisation, and even modest interventions such as the identification of a named care co-ordinator in primary care for people with long-term conditions, mental health problems and the frail elderly. Work underway in Sweden to test incentives to increase primary care responsibility for inpatient care, standardise care around discharge, risk stratify patients discharged from hospital, improve integration between primary and specialist care and managing pathways, and reforming payments to primary care to better co-ordinate care are positive moves in this direction.

Sweden's decentralised system facilitates the development of innovative local solutions. The scale of innovation and change will depend on an overt policy commitment to promoting integrated care, organisational leadership, adoption of new ways of commissioning, contracting, delivering and incentivising integrated services, the ability to marshal resources to support change, and wider adoption of successful models through dissemination and emulation. SALAR can play a key facilitation role in this process of change.

The use of information in primary care to support quality improvement, care co-ordination and quality assurance can be strengthened

Systematic data collection, a fit-for-purpose IT infrastructure and peer-to-peer benchmarking and communication are critical for improving the quality of primary care, and care continuity and co-ordination. GPs are often unaware of the variations in quality that exist within and between their practices and those of their peers. Making clinicians aware of such variations, through use of appropriate data and information tools, is a first step to enable them to explore and address the reasons for variable performance. Examples of where a strong tradition of standardised analysis and benchmarking in general practice has led to quality improvements include the QOF in the United Kingdom; although not incentivised, the Quality Indicators in Community Healthcare used to monitor the quality of preventive, diagnostic and therapeutic primary care services in Israel; the Danish General Practice Database which, as well as being able to identify individual patients that are sub-optimally treated, allows practices to benchmark themselves against other practices at municipal, regional, and national levels.

Improved information would support the regulation of primary care by the national inspectorate, and accreditation of providers, quality assurance and monitoring of the implementation of national standards by local government. Greater standardisation of quality standards in primary care, and the criteria for accreditation, would enable more effective monitoring of quality across primary care providers on a consistent basis nationally. This would support more effective execution of the regulation and quality assurance functions, and provide better comparative information for patient choice.

Access to good data also supports many other important functions such as assessment of local health care needs, risk stratification of patients with intense care needs, patient choice and public accountability for taxpayers' money. Better information availability, transferability between providers, and data linkage are fundamentally important for improving care co-ordination and continuity.

Section 2.3 describes the current status of data availability and use in primary care in Sweden. With primary care accounting for almost 20% of total health expenditure and a high volume of contacts, it is imperative to have fit-for-purpose information for monitoring the quality of primary care. This requires national solutions that, as a first step, enable standardisation in IT systems and electronic records, data collection and compilation across primary care. As a second stage, IT solutions that enable record linkage, transferability and inter-operability across different care settings would greatly enhance progress towards Sweden's goals of reducing use of hospital services and improving care co-ordination. For example, linkage across quality registers can be used to identify patients with complex care needs who can then be assigned care managers. Although several countries have restrictions on the use of linkage across electronic information systems due to concerns about privacy, it is possible to do this in a safe IT environment that does not compromise patient confidentiality, and several countries routinely use linked data to support better patient care.

The lack of a national information architecture and IT framework, including for the quality registers which have developed from the bottom up, are challenges that Sweden is starting to tackle through its national IT strategy. National projects aimed at developing a summary electronic record for use across care providers, integrating information systems and implementing SNOMED CT nationally are underway. However, implementation via such national solutions could potentially be slow, given the strong tradition of localism and devolved government, the required amendment of legislation and regulations, and the standardisation and upgrading of the IT infrastructure needed to support inter-operability and sharing of patient records across providers. Investment in developing the primary care information base and expediting the implementation of government policies in this area should be a priority.

Sweden's quality registers serve as an international example of best practice in terms of tracking patient care and outcomes over time. There is strong professional commitment in Sweden to the development and use of quality registers, and robust evidence of how they have supported quality improvement in many areas, especially in secondary care. Quality registers need to be better embedded in primary care, to optimise the potential for quality improvement across the entire patient pathway. A Swedish example of the effective use of data in primary care is the prescribing data linked to patient demographics and clinical details, leading to a fall in unsuitable use of medication in the elderly, e.g. poly-pharmacy and neuroleptics. Such examples can become the norm if ensuring that primary care activity is adequately captured in the quality registers becomes a priority. However, populating many quality registers could impose an unsustainable burden on primary care, or result in staff capacity being diverted from patient care. Hence IT solutions enabling, for example, downloads from standardised electronic patient records should be the way forward.

The quality registers also offer excellent development opportunities. Some data linkage of the registers, including to mortality, is already underway, with significant potential for extension. Use of standardised electronic records and data linkage would also reduce the burden on primary care staff of recording duplicative data in multiple quality registers.

The information and IT developments underway appear to be targeted primarily at improving public access to information and to support patient choice. Enhancing, standardising and streamlining the information architecture to support improvements in health care quality and co-ordination, including in primary care, should also be a priority. In addition to tackling some of the practical issues entailed, leadership and a culture change in primary care will also be needed to overcome resistance to data collection by promoting the potential of benchmarking data for quality improvement and supporting patients.

The primary care workforce will need to be adequately staffed and appropriately skilled to meet the challenges that lie ahead

As in many countries, the challenges facing primary care in Sweden will grow – in both scale and complexity. Additionally, care is moving from hospitals to the community, and primary care is increasingly required to extend its remit to formally encompass a wider care co-ordination role. Ensuring an adequate complement of primary care staff, that also has the requisite training and skills to meet these challenges, will be essential if primary care in Sweden is to raise its game over and above the current high standards.

Although GP numbers in Sweden have increased significantly over the past decade, the lack of ongoing, centrally available data on the workforce and their productivity makes it difficult to assess reliably the adequacy of GP numbers. The government estimates there is a shortage of GPs. Given the long lead time for training, it is important to have long-term, national workforce planning strategies that ensure recruitment initiatives meet projected needs, rather than relying on ad hoc local action by county councils. Similarly, a co-ordinated strategy will be needed to ensure adequate numbers of primary care support staff, nurses in particular, given drop-out and retirement effects.

While the model of primary care in Sweden is potentially well-suited to meet the challenges of delivering high quality, integrated care, it will be important to ensure that workforce competencies remain of the highest standard. Sweden’s informal arrangements for continuous professional development (CPD) diverge from the formal CPD requirements for GPs in many countries. The United Kingdom, for example, has introduced an annual appraisal and five-yearly revalidation process that is mandatory for GPs, and practices have to meet minimum national quality standards in order to register with the national regulator, the Care Quality Commission, as a license to practise. While the United Kingdom may have gone further in this regard than most countries, the need for formal CPD schemes for medical professionals as a way of ensuring fitness to practice is recognised in many countries, and warrants consideration in the context of Swedish GPs. Training and CPD for GPs should encompass the skills set required to provide and co-ordinate care, including palliative care, for older people and for those with complex conditions and mental health problems.

Although practice nurses already play an active role in the delivery of primary care in Sweden, their contribution can be enhanced further by developing their skill-set further, extending their roles (for example in prescribing), and redefining their roles in care co-ordination and home health care services.

2.5. Conclusions

Quality and health outcome indicators for Sweden are among the best internationally, reflecting the contribution of its high quality health care system. Sweden's well-developed and highly skilled primary care sector has played a key role in these trends. Structural reforms in Sweden over the past decade have seen a shift of care from the acute hospital sector towards primary and community care, which has helped to further improve quality and contain health care costs. The growing demands on health and social care services, a tight fiscal environment, and rising public expectations, means this process needs to go further. Moreover, the growing complexity of health care needs and technologies, rising prevalence of multi-morbidities, and the increasing duration for which most people need health and care services, has made care co-ordination and integration of paramount importance.

The multidisciplinary skill base and competencies of Swedish primary care are a national asset. They offer considerable potential for further improvements in the quality of care, through both primary and secondary prevention, and a stronger role for primary care in co-ordinating care across different settings. Primary care provides the first and long-term point of contact for most of the population. It is therefore well positioned to ensure continuity of care and act as the co-ordinating hub across multiple providers and interfaces, although this function would be greatly facilitated if primary care in Sweden had a formal gate-keeping role.

Progress towards these goals will depend on having a facilitatory policy environment, the willingness and ability of county councils and municipalities to work together and with primary care, and the willingness and capacity of GPs to formally take on this wider role. The government will need to ensure that there is a clear strategic vision for primary care shared by SALAR, county councils, municipalities and leaders in primary care; the reforms on choice and competition promote co-ordinated care and avoid fragmentation; and payment and incentive systems foster co-operation, co-ordination and joint working. Primary care will need to be adequately resourced. To meet the increasing demands on primary care, an adequate supply of GPs and other primary care staff will be needed. They will need to be appropriately trained and flexible, including to provide care for complex patients, and systems for continuous professional development should be in place to ensure their skill-set is kept up to date. Innovative local models of integrated care, such as already exist in Sweden's devolved health and care system, should be encouraged. Finally, improvements in the quality, consistency and coverage of primary care data, accompanied by stronger, standardised systems for quality monitoring, assurance and regulation will be essential for supporting quality improvement and care co-ordination in primary care.

Note

1. Kaiser Permanente – United States; Pace – United States; Torbay Care Trust – United Kingdom; PRISMA – Canada; Personal Health Budget – Netherlands; Personal Care Record – Singapore.

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Chapter 3

Long-term care in Sweden

The Swedish long-term care (LTC) system for frail and dependent old people is comprehensive in many respects. It offers good financial protection and covers a broad range of services; is mainly funded through public sources; and is staffed with a large number of care workers by OECD standards. Long-term care services are organised at local level, with municipalities purchasing care from both public and private providers, and many LTC recipients have the possibility of choosing across competing providers. There has been limited measurement, however, of the effectiveness and safety of care, and few mechanisms for guaranteeing standards of quality of the services of the type found in health care.

Given the significant public investment in LTC services in Sweden and the expected growth in the number of frail old who might have complex care needs, there is an urgent need to bring about a high level of transparency about outcomes of care. At the same time, a quality system that assures competence and minimum care standards across the country is also needed.

Recent reforms offering financial incentives to municipalities that meet quality targets in specific areas such as reductions in unnecessary hospitalisations of old people or use of inappropriate drugs are a step in the right direction. These initiatives should encourage increased effectiveness in elder care. They should be complemented with other actions to facilitate sharing of data across the health and LTC sectors, whilst incentivising the replication of successful local examples of service integration.

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

3.1. Introduction

Sweden is internationally regarded as a model for long-term care (LTC) for the frail and dependent elderly. The system is impressive, with very generous coverage, little cost-sharing at the point of service, a wide use of assistive and adaptive technologies and a strong emphasis on improving elderly well-being by encouraging them to remain at home for as long as possible.

Sweden spends more than most other OECD countries on long-term care. As a share of GDP, Sweden's public expenditure on LTC was as large as 3.6% of GDP in 2011, second only to the Netherlands (whose spending also includes younger disabled groups), and more than double the OECD average of 1.7% of GDP. This expenditure is projected to increase over the coming years. While the growth in the over 80 years age cohort between now and 2050 will be less dramatic than that of other OECD countries and, whilst disability trends are consistent with a healthy ageing hypothesis, projections from OECD and the European Commission show that spending on LTC in Sweden will more than double by 2050.

For this high level of public spending (and related high level of taxation), there ought to be high public accountability and transparency regarding LTC outcomes, such as efficiency, quality of LTC services, and ability to deliver a holistic set of services for frail and dependent elderly people, across the health and social care sector.

Accountability and transparency in LTC outcomes is also important because the governance structure for LTC in Sweden is based on local and decentralised levels of governments having main responsibility for care services and guaranteeing quality. However, there are few incentives for co-ordination between municipal LTC services and health care services for old people delivered by counties. Recent reforms have aimed at driving efficiency and quality in LTC by fostering users' choice and competition across service providers and by setting performance based incentives. For this quality-assurance governance model to deliver the high level of performance and accountability that is to be, it is important to establish supporting levers, tools and checks across the system. These include the provision of good and transparent information on LTC quality, high level of competences for the LTC workforce, strong co-ordination incentives/mechanisms with health care and governance mechanisms to drive the system towards higher quality.

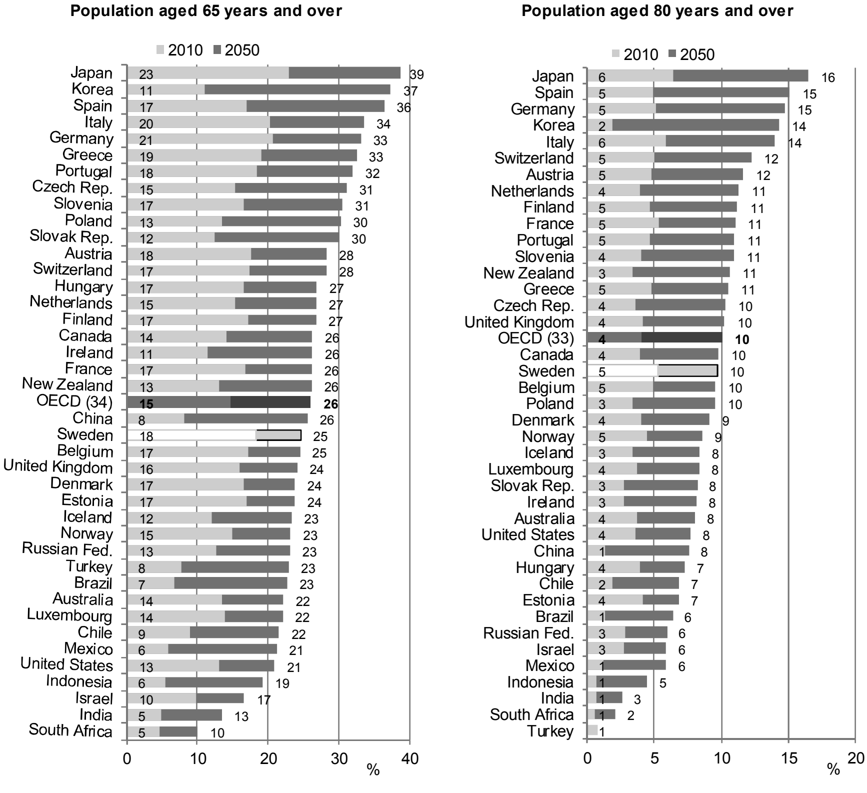
After describing (with international comparison) the LTC system in Sweden, this chapter assesses the performance of the Swedish LTC quality assurance-model and analyses the extent to which the system provides the tools and levers to drive high quality, accountability and co-ordination.

3.2. Comparing long-term care in Sweden to other OECD countries

Sweden has a favourable demographic outlook and good health indicators in old age

In 2013, 19.4% of the Swedish population is aged over 65 years, compared to an OECD average of 16%, while 5.2% of the population is aged over 80, compared to an OECD average of 4.2%. Demographic projections signal that the share of the population over 65 and over 80 years will increase, but will remain below the OECD average by 2050 (Figure 3.1 compares demographic data for Sweden and other countries for 2010 and 2050).

Figure 3.1. Sweden is predicted to have a slower rate of increase of the shares of the population over 65 and 80 years in 2010 and 2050 across OECD countries



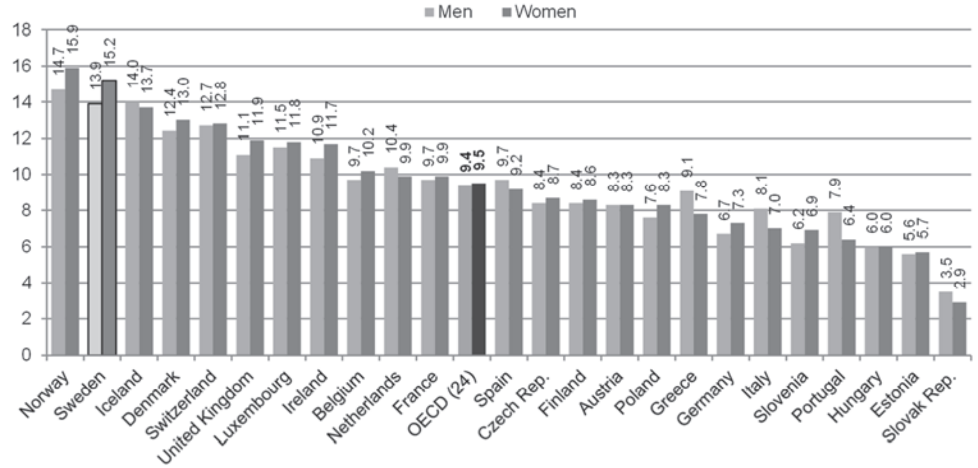
Source: OECD Historical Population Data and Projections Database (1950-2050), available at http://dotstat.oecd.org/Index.aspx

Today, average life expectancy in Sweden is 84.4 years and is expected to rise by 2.6 years by 2050 (NBHW, 2010). At age 65, life expectancy was 21.3 years for women and 19.3 for men in 2011, higher than the OECD averages of 20.9 and 17.6. Gains in life expectancy at age 65 have been similar to the OECD average, namely six years since 1960 (*OECD Health Statistics, 2013*).

Furthermore, the Swedish elderly population has good health indicators:

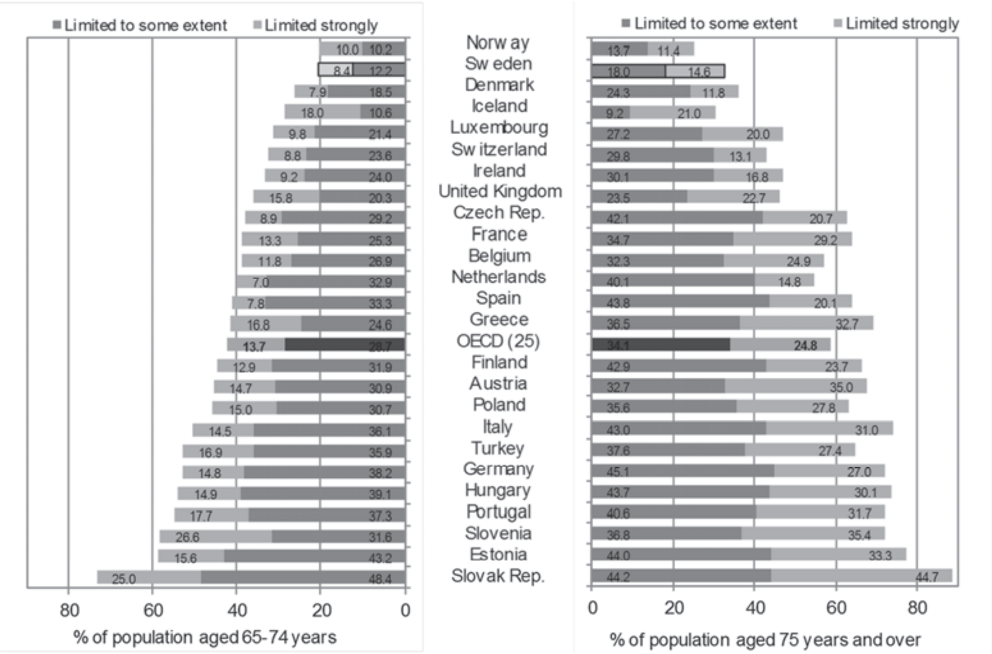
- Sweden has among the highest healthy life years – years that a person can expect to live in a healthy condition – at age 65 in the European Union (see Figure 3.2). Swedish 65-year-old men are expected to live 14 more healthy years and women are expected to live 15 more healthy years. These figures contrast with an average across the European Union of 8.6 additional healthy years for men and 9.5 additional years for women in 24 OECD countries (Eurostat, 2013).
- Elderly people aged between 65 and 74 in Sweden have fewer limitations in daily activities than any other EU country but Norway, and those aged over 75 have fewer limitations than any other EU country but Norway and Iceland (Figure 3.3).

Figure 3.2. Sweden's healthy life years at the age of 65 in the European Union



Source: Eurostat (2013), "Healthy Life Years in 2011", available at http://epp.eurostat.ec.europa.eu/cache/ITY_PUBLIC/3-05032013-BP/EN/3-05032013-BP-EN.PDF.

Figure 3.3. Limitations in daily activities, population aged 65-74 and 75 years and over, European countries, 2011



Source: Eurostat Statistics Database 2013.

Sweden has a comprehensive but expensive long-term care system

The Swedish LTC system offers good coverage. All citizens, regardless of income, insurance or other personal circumstances are entitled to publicly funded medical and social care services (Stolt et al., 2011). More than one in six people aged over 65 years received care services in 2011, above the OECD average of 12% (Figure 3.4). The depth of coverage, i.e. the type of services covered, is also wide (Box 3.1).

Unsurprisingly given its good coverage, LTC spending as a share of GDP in Sweden is second only to the Netherlands (Figure 3.5). This is well above other OECD countries with larger elderly populations such as Japan, Italy and Germany. Public LTC expenditure accounts for the largest share of spending; Sweden has one of the lowest levels of private out-of-pocket spending for LTC in the OECD (Colombo et al., 2011).

Expenditure projections suggest sustained spending growth over the coming decades. The European Commission (2012) projects that, by 2050, public expenditure on LTC will account for 5.7% of GDP, increases that are consistent with local projections. These projections raise questions about longer-term fiscal sustainability and raise expectations that additional spending will deliver good quality and efficient care (Bergmark et al., 2000; NBHW, 2010).

Box 3.1. Overview of the Swedish LTC system

Sweden is recognised for its universal and comprehensive LTC programme. According to the Social Services Act (2001), older people have "the right to claim public service and help to support their day-to-day life if their need cannot be met in any other way." Similarly, the Health and Medical Services Act (1983) calls the health system to maintain a good standard of health among the entire population and provide care on equal terms (Socialstyrelsen, 2009).

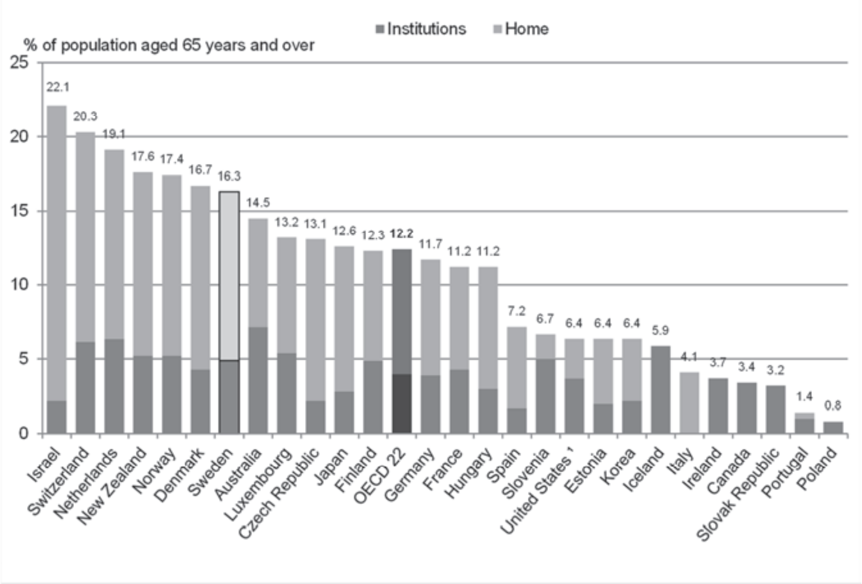
In 1992, the Ädelreformen Elderly Reform was enforced. Under this reform, the municipalities were given the overall responsibility for social care for the elderly and the disabled. These responsibilities include providing care services, managing care staff (with the exception of physicians), and responsibilities for assistance living at nursing or special houses mostly targeted to people with dementia or a high level of care needs/frailty. Currently, the county councils are responsible for providing home health services, but can transfer this responsibility to the municipalities if agreed. More than half of the municipalities in Sweden have taken over the responsibility for home health care from the county councils. By 2015, the responsibility for home nursing care will be taken over by all municipalities in Sweden.

Most LTC services are financed through local municipal taxes collected by the 290 municipalities. Municipalities levy local taxes and decide the extent to which they prioritise expenditure on elderly people over other groups (Anell et al., 2012). In 2010, 85% of total LTC spending was financed by local municipal taxes. Government grants to the municipalities, negotiated through annual agreements, cover 11-12% of the costs of long-term care. The remaining expenses of LTC is financed through user fees (3-4%). The costs paid by elderly themselves are capped and based on specific rate schedules; the level of user co-payment is income-related, after adjusting for the housing and basic necessities. There is a maximum contribution amount for home help services which effectively caps an individual's out-of-pocket expenses, safeguarding against excessively high charges.

LTC for the elderly includes both varying forms of assistance in a home environment, institutional (or special-housing) care (old people's homes, residential care, homes for the demented/dementia units, nursing homes and similar) (Edebalk, 2010). It includes personal care – such as help with bathing, getting dressed and in and out of bed – as well as help with shopping, cooking, cleaning and laundry. It also provides elderly in need with assistive devices, transportation, housing adaptations, handicap aids and support for informal caregivers. For people living in institutions, the cost of board and lodging is covered, with a co-payment based on the income of the recipient. This is more than what provided in many other OECD countries.

Source: Swedish Institute (2012), "Facts About Sweden: Elderly Care", Swedish Institute, Stockholm, available at: www.sweden.se/upload/Sweden_se/english/factsheets/SI/SI_FS8p_Elderly_care_in_Sweden/FS13-Elderly-care-low-resolution.pdf; Socialstyrelsen (2009), "Care of Older People in Sweden, 2008", available at: www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/17857/2009-12-6.pdf.

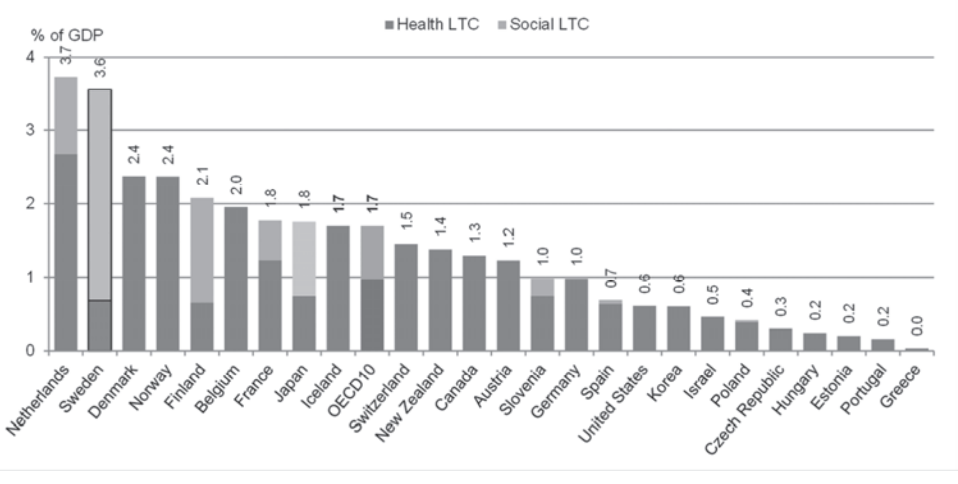
Figure 3.4. Population aged 65 and over receiving long-term care, 2012 or nearest year



Note: In the United States, data refer to 2007.

Source: OECD Health Statistics 2013, http://dx.doi.org/10.1787/health-data-en.

Figure 3.5. Long-term public expenditure (health and social components), as a share of GDP, 2012 or nearest year



Note: The OECD average only includes the ten countries that report health and social LTC.

Source: OECD Health Statistics 2013, http://dx.doi.org/10.1787/health-data-en.

Sweden elderly care governance model relies on decentralised decision making and market incentives

Four main features characterise Sweden's LTC governance model:

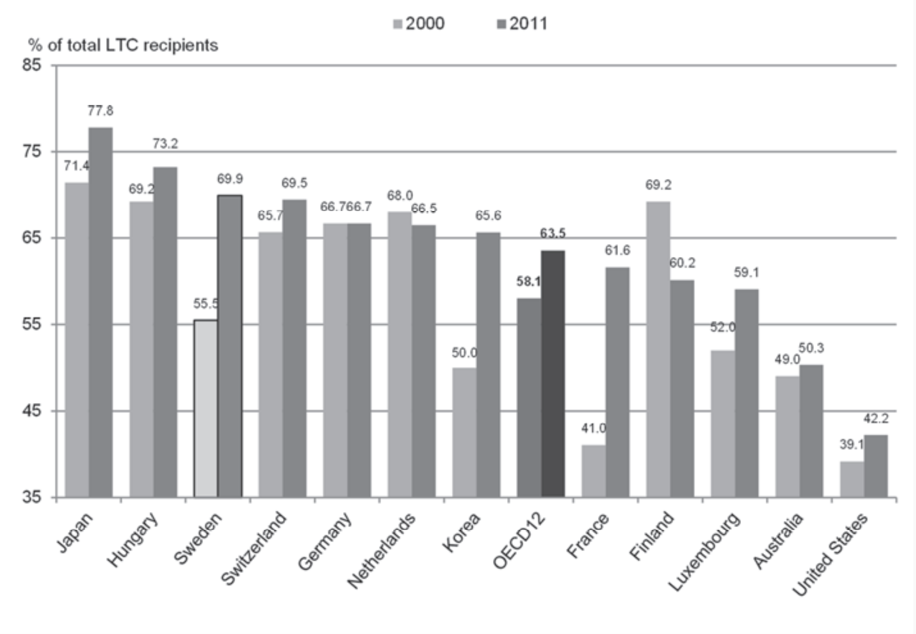
- *Decentralised governance*. While the legal framework is set a national level, both the Health and Medical Services Act (1982) and the Ädelreformen (Elderly Reform Bill, 1992) specify that care for the elderly and the disabled is organised within decentralised political structure. The 290 municipalities have the legal obligation and autonomy to provide social services, nursing and housing needs of the elderly. The 21 counties/regions are responsible for health and medical care for the entire population. Funding is based on taxes and mainly provided by the municipalities and counties themselves. One of the main aims of the Ädelreformen was to provide incentives for municipalities to organise home based elderly care – often termed as "ageing in place".

- *Focus on keeping dependent people at their home*. While the number of LTC beds still remains the highest in the OECD and well above the OECD average,[1] over the years, Sweden has emphasised provision of care for the elderly in their homes. Sweden has seen one of the most marked increased in the share of home-care LTC recipients in the OECD (see Figure 3.6). The hours allocated to home-based services and services in institutional care amounted to 4.5 million in 2009, compared to 3.8 million in 2002 (National Board of Health and Welfare, 2011 in Anell et al., 2012). Sweden has also seen the largest reductions in LTC beds in the OECD area between 2000 and 2011, with an average annual reduction of 1.2% of LTC beds in institutions and of 4% of LTC beds in hospitals, compared to a 3.7% average annual growth in beds in institutions and a 0.4% reduction in LTC beds in hospitals, across the OECD. This, along with one of the lowest number of acute hospital beds per 1 000 population in the OECD, has increased pressure on municipal elderly care (Figure 3.7).

- *Emphasis on choice and the market*. Provider competition is regarded as an important tool for driving performance improvement. The 2009 Law on System Choice in the Public Sector opened the provider market to competition across (public and private) providers of home care services, under the assumption that municipalities and recipients would choose providers based on their performance. Municipalities participating in choice system have to provider details, acceptance criteria, and quality information disclose on a national website (Svensk författningssamling, 2008). Municipalities have significant autonomy to grant licenses for operation, set prices and monitor compliance (Dandi et al., 2012). The new law also encourages municipalities to introduce quasi-voucher systems that can be used by the consumer to purchase home care services (Steuerle, 2000). The proportion of care services provided by private entrepreneurs increased from 1% in 1990 to 16% in 2010 (Stolt and Winblad, 2009). As of 2011, more than 900 providers are operating and 18.6% of all elderly people receiving home help do so through private providers (Swedish Institute, 2012).

Figure 3.6. Sweden exhibits a significant increase in the share of home care recipients

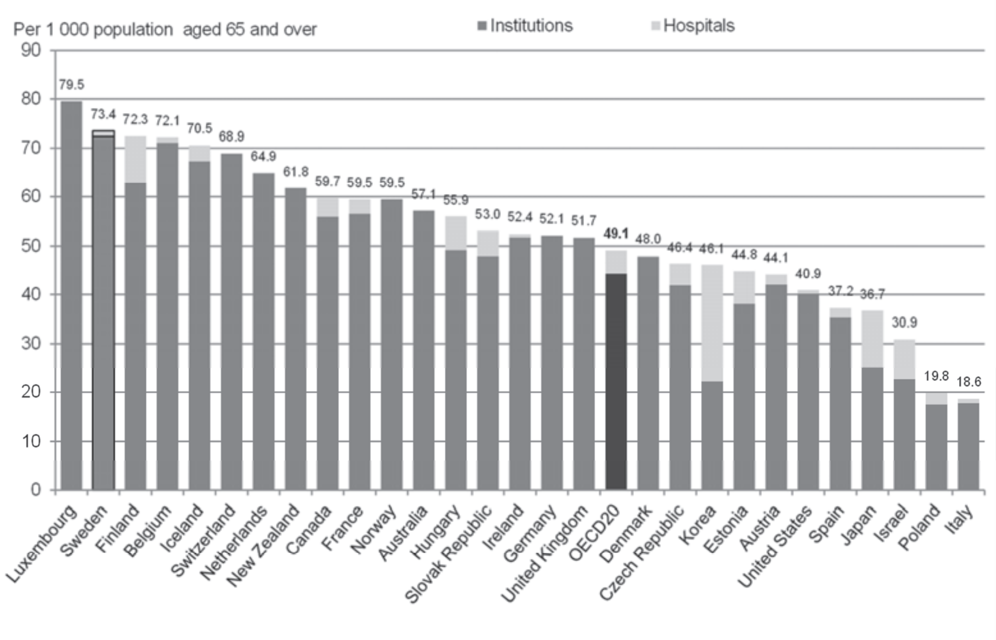
Share of long-term care recipients receiving care at home, 2000 and 2011 or nearest year



Source: OECD Health Statistics 2013, http://dx.doi.org/10.1787/health-data-en.

- *A powerful use of incentives*. Sweden has made significant use of financial incentives to steer change (via grants to local governments and dedicated funded to encourage innovative initiative). Starting in 2010, the annual transfers from the central government to municipalities have included performance targets based on outcomes results for elderly care (described below).

Figure 3.7. Long-term care beds per 1 000 population aged 65 and over, 2009 or nearest year



Source: OECD Health Statistics 2013, http://dx.doi.org/10.1787/health-data-en.

The Ädelreformen reform, the Law on System Choice in the Public Sector, and the use of conditional budget transfers have created an environment where LTC providers' performance (including efficiency and quality) is encouraged through incentives for providers to compete, for users to choose across providers, and for municipalities to deliver value and quality. For this model to function effectively, transparency of outcomes of care is a fundamental condition. People need to base their choices on measures of quality, and municipalities need to base their purchasing decisions on indicators of providers' performance and be able to compare themselves to the performance of other municipalities. In addition, relying on a model of competing providers presupposes that all providers meet certain minimum standards of care, and do not compete on lowering those standards. To what extent does the Swedish LTC system have these building clocks, necessary to maintain a good functioning of the LTC market? This is what the following sections in this chapter will assesses, focusing on the performance of the LTC system with respect to its information on quality, its quality-assurance model, and its ability to ensure co-ordination with health care services.

3.3. Strengthening measurement of LTC quality

A system with free choice of providers requires better information on quality and efficiency

For consumer choice to encourage better quality or lower costs, it is essential that information regarding services and their quality is valid, clear and accessible and that consumers have the effective ability to exercise choice across a plurality of providers (NBHW, 2009; Konkurrensverket, 2009).

An assessment of the Swedish LTC choice system suggests that not all these conditions are met. Under the current system:

- While the purpose of the reform is to promote freedom of choice in order to enhance the diversity of providers, most stakeholders believe that competition across providers has not been driven by quality, but instead by location, customer service and diversification of the services offered (e.g., public and private providers offer services that differ on things such as languages, cultural or religious competence, and specific treatments).

- It appears that some people find it difficult to choose among different providers and report that they need more support from the local municipality to benefit from this free choice system.[2] Choice of care providers may be difficult for many elders with declining physical and cognitive abilities (Meinow et al., 2011). The government is investigating how to design better support to help people make informed choices.

- There seems to be little connection between choice of services and their quality or cost-effectiveness. Some of the services provided reflect an ambition to offer comprehensive care rather than the result of cost effectiveness analyses (SALAR, 2009a), although the reform creates incentives to improve monitoring of operations (Statskontoret, 2012).

- While there are initiatives across Sweden to collect LTC service quality data (see example on Nacka in Box 3.2 and other initiatives are described in the following sections), municipalities face several limitations in this area. There is no requirement regarding how quality should be assured and Social Care Act stipulations are not easily operationalised into quality indicators (NBWH, 2009).

- While studies have shown greater satisfaction among users that exercise free choice and user studies have shown two main areas of improvements, namely meal routines and social activities, there is no robust evidence regarding improvement in efficiency. The increased satisfaction rates may indicate that the quality of home care services has improved, but it could simply signal that users appreciate the opportunity to choose their service provider (Statskontoret, 2012b). Studies in Denmark and Finland that have a system of free choice of providers show similar results (Kaskiharju and Seppänen, 2004; Ankestyrelsen, 2005; Volk and Laukkanen, 2007).

- There does not seem to be a comprehensive comparison between public and private elderly care to understand the effects of privatisation and competition among providers. One study shows that private care providers emphasise service aspects (e.g. the proportion of residents participating in the formulation of their care plan, the proportion of elderly with a reasonable duration between evening meal and breakfast, and the proportion of elderly offered different food alternatives) rather than structural quality factors (e.g. the number of employees per resident) or process and outcome factors (Stolt et al., 2011).
- Overall, it seems difficult for policy makers, providers and purchasers to evaluate the quality of LTC services and identify areas for improvement given the information available.

Box 3.2. The Municipality of Nacka facilitates informed choice of providers

The Municipality of Nacka was the first to implement the free choice system for long-term care users. It is located in Stockholm county and has 88 000 inhabitants.

In order to facilitate informed choices among their LTC users when deciding which LTC provider to choose, the municipality has implemented a publicly available online information system. Data include all LTC service providers. Granted sufficient response rates and being in operation for a sufficient time, each provider is presented with structural and user-satisfaction data, presented in the form of an index that ranges from 1 to 100%. The indicators used come from regular municipal studies, such as customer surveys and facts collected from the providers. The customer satisfaction survey is carried out yearly by an external and independent; it covers elders in home care, respite care or living in a nursing home.

Among the indicators used are: nurses per total staff, number of residents per rehabilitation staff, number of residents per total staff, number of residents per staff, percentage of recipients that feels secure with the accommodation, and percentage of residents that have confidence in the staff.

Source: Municipality of Nacka official websites, http://jamforaren.nacka.se/content/homehelp/search.aspx; http://jamforaren.nacka.se/content/nursinghomes/search.aspx.

The government launched in September 2012 an inquiry to analyse the effects of the Act of System of Choice in the Public Sector, addressing questions of quality, costs and efficiency. The report is expected by January 2014.

Recent initiatives to measure quality of long-term care are worthwhile but gaps remain

Recent initiatives to collect and improve information on LTC services offer a real opportunity to improve the information infrastructure for LTC quality. Some such initiatives are described below, while the next section will discuss ways to strengthen the system.

Having expanded the personal identifier number used in medical records to social care services, greater sharing of information ought to be encouraged

In Sweden, all individuals have a unique personal identifier that is used for electronic medical records (Ludvigsson et al., 2009). Since 2007, the use of the unique identification number was expanded to social services, meaning that municipalities are obliged to collect data using the unique identification number regarding the use of municipal services. This offers an opportunity to follow LTC patients and collect data on the quality of services provided as well as outcome indicators, which does not seem to be fully utilised as yet through, for example, linkages of data across more than one data source. Another useful development may be to identify the health care professionals entering data into electronic health records, for purposes of ensuring and validating the completeness and accuracy of the record and for statistics related to quality, efficiency and performance (OECD, 2012).

Registers of LTC users with specific conditions are expanding coverage

Sweden has a long tradition of national quality registers for specific medial diagnose or conditions (73 health and medical registers receive central funding). They contain individualised data concerning patient problems, medical interventions and outcomes after treatments. There are no specific registers for LTC users, but four registers collect information relative to elderly care for specific conditions (the Palliative Care Registry, the Senior Alert Registry, the Dementia Registry and the Behavioural and Psychotic Symptoms in Dementia Registry) (Box 3.3). These offer providers the opportunity to monitor results over time and compare their results with those of other providers. Coverage of the registries varies though. To motivate care providers to report to the registers, the Swedish Government has introduced a grant system which rewarded municipalities for achieving high reporting rates to the registers (amounting to nearly SEK 1.2 billion in 2012). By 2012, coverage of these four quality registers had increased, although remains lower for the two dementia registers introduced later (see Box 3.3) (Statskontoret, 2011a). Despite this coverage improvement, the extent to which the registries are used to drive quality improvement remains unclear. This means that providers might have little incentive to supply the data if they cannot see a direct benefit to their practice.

Box 3.3. Four registers collect information relative to elderly care for specific conditions

The *Palliative Care Registry* (2007) addresses those involved in end of life care. It collects information on structural inputs (such as beds and access to staff, care plan) associated with end-of-care, as well as information about fatalities. In 2011, 53% of deaths were recorded in the registry (www.palliativ.se).

In the *Senior Alert Registry* (2009), individual data on falls (incidences), pressure sores and malnutrition are registered. The aim of the registry is to prevent health problems among the elderly (at home and in institutional care) by identifying elderly at risk to initiate early preventive interventions. The registry also gathers reports on the follow-up of preventive activities. At present, 274 of the 290 Swedish municipalities have reported data to the registry and it has reached near complete coverage (90%) (www.senioralert.se).

The *Swedish Dementia Registry* (SveDem, 2007) aims to improve quality of diagnostics, treatment and care of patients with dementia disorders. Patients newly diagnosed with a dementia disorder are registered and followed-up yearly. Age, gender, heredity, BMI, MMSE scores, diagnoses, dementia work-up investigations, medical treatment, support from community, time from referral to diagnosis are examples of the information contained in the web-based registry (www.swedem.se). The objective is for all new dementia cases to be part of the register. In 2011, around 25% of cases were covered in SveDem. A year later, in 2012, coverage increased to 50%. By the end of 2012 SveDem had 27 000 registered patients, 11 000 of which were followed-up. 708 units were affiliated (compared to 80 in 2010) with 58 memory clinics (98% of all memory clinics) and 650 primary care units (50% of all primary care units) affiliated.

The *Swedish Registry on Behaviour and Psychiatric Symptoms in Dementia* (BPSD, 2010) aims at registering individual data on care and treatment of demented persons with behaviour and psychiatric symptoms (www.bpsd.se). All included persons are assigned a score using the Neuro Psychiatric Inventory, and basic information such as diagnosis, age, gender, medications used and different non pharmacological care interventions applied are registered. BPSD profiles are created and the different interventions applied are followed up and evaluated continuously, with automatic feedback given to the teams for making quality improvements. To date, 216 municipalities and 1 505 units, nursing homes and BPSD-teams in specialised clinics participate in the registry which monitors 5 350 patients. The registry is being expanded rapidly throughout the country. This information is used to gather knowledge on BPSD prevalence, BPSD prevention and management and quality improvement (ALCOVE, 2013).

Source: OECD questionnaires and ALCOVE (Alzheimer Co-operative Valuation in Europe) (2013). The European Joint Action on Dementia. Synthesis Report.

National user satisfaction surveys

Since 2008, national-level user satisfaction surveys measure the satisfaction with long-term care services across municipalities and units. Surveys cover home and institutional care recipients. The survey generates a Customer Satisfaction Index (CSI) capturing perceived service quality. Results show social care services rated positively by users and those that can be improved. This represents a good tool for purchasers to identify areas for improvement.

Sweden is also undergoing initiatives to make data accessible and transparent.

The Quality and Efficiency reports promote performance comparisons on quality and efficiency and motivate local governments to improve

The *Quality and Efficiency* reports produced by the National Board and SALAR present indicator-based comparisons of health care quality across various Swedish regions, counties and municipalities, as discussed in Chapter 1. These reports help policy makers at central level get a picture of variations across country, and motivate counties performing below their peers to act to improve quality of care. They are also useful for families, care personnel, managers, and private and public providers to access comparative data about service and care (NBHW, 2009, 2010). Long-term care services quality indicators included in the *Quality and Efficiency* reports have increased over the years. The 2012 *Quality and Efficiency* report, “Care for the Elderly”, includes more than 30 elderly health and social care indicators. They relate to process and structural aspects of quality, such indicators on staff continuity, influence and participation, safety, living environment, food and mealtime environment, outdoors and social activities, falls, malnutrition and pressure ulcers and elderly mental health (Sveriges Kommuner och Landsting och Socialstyrelsen, 2013). A handful of other OECD countries (e.g. Germany and the United States) publish reports on LTC services evaluating their performance, in a similar manner to the *Quality and Efficiency* reports (OECD, 2013).

The Elderly Guide

The Elderly Guide is another government initiative to improve access to information. This web-based guide for older people and their families[3] provides information on home help services and institutional care, such as on service accessibility, user involvement, staffing, training, continuity of care personnel, user independence, physician’s involvement, review of drug use/prescriptions, preventative nursing care and services, management, follow-up and information availability. The main source of data comes from special annual surveys, user satisfaction surveys and, to a lesser extent, from registry data. The amount and quality of the information in the guide could be improved by adding more data collected from registers and providers (NBHW, 2009).

KOLADA database offers guidelines for municipalities

KOLADA is developed by the Council for the Promotion of Municipal Analyses (Rådet för Främjande av Kommunala Analyser, RKA[4]), a non-profit organisation created in 2006 from a partnership between the government and the Swedish Association of Local Authorities and Regions. KOLADA is an online database that contains information gathered from official statistics on the cost, scope and quality of social services provided by municipalities and counties.[5] It enables local governments to make comparisons between municipalities and counties. RKA also provides guidelines for municipalities to collect and publish their own quality data. Using the KOLADA data, RKA has published three reports summarising the data available at the municipal and county level, covering 179 of the 290 municipalities.

Strengthening the information system for LTC quality

Despite the many efforts to collect data on service quality and to make this information accessible, transparent and comparable, there are opportunities for strengthening the system and addressing its gaps.

Expanding the scope and coverage of the data, as well as data linkages

Measures to expand the scope and coverage of data in the LTC sector should focus on developing the range of outcome measures examined, including a broader range of user experience measures, motivating providers to participate more consistently in data reporting and exploring the possibilities to link data at the individual patient level, to get a more complete picture of the quality of care services they use.

Regarding the first of these actions, most LTC quality data available in Sweden refer to processes and structures, not yet outcomes. Although structural and process measures are an important aspect of care quality, they are only indirect measures of performance. Outcome indicators – things such as prevalence of pressure ulcer, incidence of falls, incidence of use of physical restraints, prevalence of unplanned weight loss or incidence of depression – will allow LTC service professionals and managers to check whether particular interventions have resulted in improvements and identify what needs to be improved. Outcome-based indicators may also help regulators and purchasers better understand what they are purchasing. Other

OECD countries collect such indicators. Finland, Canada and the United States, for example, uses interRAI assessment instruments to generate quality of care indicators. Portugal has set up an integrated network of LTC providers supplying data to an online data management system (GestCare CCI) recording referrals, admissions, transitions, waiting times for admission, as well as outcomes of care.

In terms of the measurement of user experience and quality of life, user satisfaction data are currently aggregated to the municipal or unit level. However, these indicators represent service-satisfaction rather than a systematic assessment of user experience and quality of life. Low response rates and a high proportion of proxy- respondents (e.g. recipients' relatives) undermine the validity of the measures reported (NBHW, 2009; Socialstyrelsen, 2011). A future development would be to strengthen consumer satisfaction surveys to develop measures of quality of life related to LTC services and impact on recipients. Operationalising the concept of quality of life into metrics or indicators has proved difficult, but efforts to incorporate quality of life into national reporting systems have emerged in other OECD countries. England, Denmark, Austria, and Finland have begun using the Adult Social Care Outcomes Toolkit (ASCOT), a tool to capture individual quality of life (OECD, 2013; HSCIC, 2012). The Netherlands collects several outcomes indicators along with measuring user experiences in LTC through a standardised system (Consumer Quality Index).

Regarding means to motivate providers to participate more fully in data reporting, most Swedish municipalities are covered in two of the four quality registers related to the elderly, namely the Senior Alert and the Swedish Palliative Registry. However, the fact that a municipality contracts with providers does not mean that all the care providers report data to the registries. Private and public providers have different participation rates in quality registries. Incentives payments to expand the coverage of registries are targeted to municipalities, not to providers per se. Even when providers are aware of these monetary incentives to report, they are not necessarily motivated to report because they may not see a direct compensation or benefit from reporting (Statskontoret, 2011a). The challenge is to increase the responsiveness of providers (especially private providers) to report data to the registries by showing how quality registries can be used to improve practice, and by working with registry holders and professionals to quality information included in the registries.

Exploring the possibilities of data linkage at individual patient level is also needed. There are two main opportunities for taking advantages of the existing data for improving quality monitoring. The first is by linking information contained in registries to other information, for example by linking individual information on dementia in the dementia registry with depression, alcohol use and falls to provide a holistic picture of need. A second area would be to make more effective use of the unique identification number by sharing and linking information across health and care settings. This will require addressing capacity and privacy challenges. The extent to which municipalities keep LTC use records varies because not all municipalities have computer systems adapted to register and extract the information (NBHW, 2009). Health and social care have their own specific legal frameworks complicating the possibility of sharing information across sectors and current privacy policies prevent the use of personal information to evaluate the performance and quality of LTC services. A committee is currently investigating the possibilities to improve the exchange of information between different providers and professionals in social and health care (report expected in December 2013) and it seems important to purse this route without hesitation. Sweden can learn from the experience of other OECD countries that have unique identification numbers and are using them to track patients along different stages of the care path. Within their legal frameworks, Korea, Finland and Canada are able to link personal health and health service records for monitoring and research purposes. In all these countries data security and the protection of data confidentiality is given considerable attention to safeguard user privacy (OECD, 2012).

Improving the technical capacity and infrastructure to collect data

Municipalities are mandated to collect and report data on LTC services to receive national incentive grants. Despite this obligation, many small municipalities have too few resources to collect data (e.g. lack of computers and technical capacity) (NBWH, 2009; Progress, 2010), suggesting an opportunities for forming joint collectives to centralise this function and harness economies of scale. A linked issue will be to help municipalities (through guidelines and training) on how to collect measures of performance of LTC services. This is also relevant for the LTC registers, where the quality of the information recorded varies (Statskontoret, 2011a). A good example of improving the capacity of LTC providers and workers to collect data is the Palliative Quality Register, which received additional funding to train eight educators to teach providers how to collect and use data.

Given the decentralisation of care provision and the lack of an infrastructure that links care providers, much of the information collected by care providers is not connected and sometimes duplicated. The privacy policies governing data also limit the use of the available information for quality measurement. There is therefore ample scope for upgrading the technological infrastructure to facilitate data consolidation. The Ministry of Health and Social Affairs, SALAR, and several national health authorities have been developing a national strategy to improve user friendliness and the access to data and amend laws and regulations governing data use (SALAR, 2009b). Continuing efforts in this direction should be a priority.

Improving capacity to analyse and use the data

To be useful for users in guiding their choice, LTC information needs to be targeted at user needs and be easily accessible. Accessibility to the information contained in the Elderly Guide may be limited because it is only available online and many elders still have limited digital access (Selwyn et al., 2003). Other delivery formats for the Elderly Guide could be considered to make the information as widely available as possible. Finland, for example, has handbooks directed at service recipients and their families, describing the rights and obligations according to the health and social services legislation, and providing practical instructions (OECD, 2013). In France, specific information is available by phone: a French national dementia help-line provides information and directs people to their nearest local agency (Cahill et al., 2012).

In the United States, the Nursing Home Compares website provides detailed quality information on individual facilities including inspection results, quality measures, a five-star quality measure and comparison to state and national measures. Evaluations suggest modest positive impact for consumers, providers, regulators, hospital discharge planners, and care managers. The municipality of Stockholm (and subsequently several other county councils and municipalities) is currently implementing Older Direct, an initiative where elders can get information about local elderly care services and receive help to choose among providers.[6] There is scope for municipalities to join efforts in implementing these kinds of initiatives.

There is a recognition that greater capacity at local and decision maker level would improve service quality and allow for decisions regarding LTC services that are based on cost-effectiveness (SALAR, 2009). For example, while coverage in the four quality registers has increased, the potential for using the information contained in the quality registers to follow up on the results of care services is not fully realised (Statskontoret, 2011a). There are already good examples in Sweden. Elderly Alert is a *preventive care* register for any elderly citizen who comes into contact with health services or social care. By recording whether certain preventive checks have been made (continence, bed sores, falls and malnutrition) and what action taken, it provides useful guide and feedback to practitioners.

It would be important to work with providers and municipalities to assess how the quality information contained in the registries could be enhanced, or to evaluate the opportunity to adopt standardised assessment instruments to improve ability to collect a minimum set of outcome indicators. The Canadian experience offers a useful example in this respect. A consensus building process was used to reach agreement between clinicians, administrators, policy makers and researchers on the type of information needed to support care improvement and on selection of information standard. Second, collection of information was mandated ensuring full implementations across provinces, providers, and settings (OECD, 2013).

Another critical issue is to provide feedback at all level of implementation of any framework for collecting LTC quality measures. While providers need information feedback almost instantly, managers need information on a longer time frame to support decisions, and governments need period information to inform population decisions. It will be critical to build in ways for these different players to receive the information they need to inform their decisions. In the United States, for example, 16 quality measures are collected quarterly from the Minimum Data Set, a uniform assessment instrument for institutional care recipients, completed at regular intervals (OECD, 2013).

3.4. Reinforcing quality assurance to complement transparency and competition

Sweden has only weak quality assurance mechanisms for LTC

Sweden’s quality assurance system relies mostly on self-regulation, inspection and a right to appeal. The quality assurance system for LTC is grounded on the general legal framework of the Social Services Act of 1982. This specifies that everybody has the right to claim public services and help to support their day to day existence if their needs cannot be met in any other way. If an elder is dissatisfied with the quality of the services he/she receives, the recipient has the right to appeal in an administrative court. Inspected facilities are those deemed “high risk” and those with a large number of complaints.

There are risks in relying on *ad hoc* inspections and self-regulation as dominant quality assurance model, particularly as most care recipients will be cared for in their homes and the complexity of care needs in institutional care is growing. Decentralised governance also means that there is a risk of high variability in quality across localities, and unacceptable levels of quality at the low end of the spectrum. Sweden’s LTC services would benefit from a better structured quality assurance system entailing, for example:

- the possibility of introducing standardised needs assessment process
- some form of accreditation and re-accreditation system to regulate providers entry and practice (e.g. nursing homes, assisted living programmes, home care)
- greater use of guidelines and protocols for care
- establishing minimum qualifications for LTC workers.

The need to move towards a more comprehensive quality assurance model is not unique to Sweden. Few OECD countries have set quality standards and assurance models. Those who have done so, mostly focus on regulating staffing levels and qualifications (Finland, Spain, Germany, Japan), physical structures (the Netherlands, Austria, Japan) and in some cases service structure at a system level (for example municipalities in Finland have set targets on access to different types of services of those aged 75 and older) (Niels et al., 2010; OECD, 2013). Considering how well developed and comprehensive are long-term care services in Sweden, it seems important for the country to take an active lead in setting a model not only for coverage of care needs but also for quality assurance in LTC.

Sweden should consider the use of standardised tools to guide its needs' assessment process

Sweden uses a comprehensive and subjective system to asses individual care needs that takes into account the individual, social and family conditions of care recipients. Citizens requesting services approach the "care manager" – a municipal employee – who determines eligibility and the level and types of service for which the applicant is eligible. This model is built on trust in the care managers' professional decision because there are no standardised instruments or guidelines to support the process. Care managers assess applicants' needs through interviews with the person requesting care. Eligibility is based on cognitive and functional limitations, and is not means-tested. Citizens are entitled to appeal the care-managers decision to an administrative court if he/she is not satisfied with the decision.

Sweden's individualised and non-standardised approach to LTC needs assessment comes in contrast to a growing number of OECD countries that have adopted standardised instruments for the needs assessment. These are typically used by clinicians, registered nurses, trained LTC workers or case managers to appraise the physical, cognitive and functional needs of LTC users and rank their level of impairment into scales and indices. The central government has commissioned the National Board of Health and Welfare to develop standardised methods and instruments for needs assessment, whose results are being implemented on voluntary basis in the municipalities. It is expected that by 2015-16 data collected with this tool would be linked to national reporting and statistics system.

While it is not easy to strike the right balance between the standardisation of assessment and tailoring of care to individual needs and circumstances (especially when considering broader concepts like quality of life and patient centeredness), systems like in Sweden that focus on individual circumstances to assess needs are not incompatible with standardised assessment instruments. Many OECD countries using standardised assessment distinguish clearly between the (standardised) process of assessment which ensures uniformity in assessment of need, and the (tailored) process of deciding on benefit entitlement and drawing a care plan, which can be adjusted to individual needs and circumstances (e.g. Japan, Spain, England's proposal under the 2012 White Paper "Caring for Our Future", France).

The advantages of using standardised needs assessment in LTC include (OECD, 2013):

- facilitating the normalisation of care processes and driving care processes towards desired quality benchmarks, including through the application of practice guidelines, protocols and expert standards
- preparing tailored care plans and highlighting potential areas of concern and risk. Such plans can ensure effective provision of care and help to collect data on the evolution of needs
- facilitating the planning of continuity of care across different care settings (nursing homes to home care, mental health, palliative care, and post-acute care)
- collecting comparable data across providers, and helping governments identifying where care needs are the highest and support targeted resource allocation
- reducing subjectivity in the process of assessing nursing needs
- applying care guidelines consistently across users and facilitating interdisciplinary teamwork (OECD, 2013).

Notwithstanding the benefits associated with a standardised needs assessment process, several challenges need to be kept in mind (OECD, 2013). For example, even when needs assessment processes are well developed, their use in developing standards of practice, drawing comparisons between individual data and practice standards or guiding nursing-staff clinical decisions may be inconsistent.

There is scope for more widespread use of guidelines and protocols to standardise care processes

Protocols, guidelines and expert standards provide useful recommendations for the management of frail elderly given the complexity of their needs and multiple vulnerabilities (OECD, 2013). In Sweden, some initiatives promote the use of national guidelines for specific LTC conditions. The scope and use of guidelines and protocols in elderly care could be further expanded:

- Existing national guidelines used for care of elderly people (e.g., substance abuse, schizophrenia, dental care and stroke) are mostly focused on hospital care and their scope could be expanded to cover other clinical settings, including social care. Examples of where this has been done include the dementia guideline and the ProCare guideline (see Boxes 3.4 and 3.5).
- There is scope for making better use of clinical registers. A good example is Behavioural and Psychological Symptoms of Dementia register, which functions as both a clinical guideline and a register. The register records behavioural disturbances (such as apathy or aggression) and advises on prevention and management of the conditions.
- Development of non-disease specific guidelines to take into account the care needs of elderly people with more than one long-term condition should be considered.
- The adoption of existing guidelines could be encouraged. The National Board of Health and Welfare in partnership with local authorities is allocating funds to municipalities to support dissemination and implementation of national guidelines in the years 2012-14. The Swedish Dementia Centre, together with the National Board, is also encouraging adherence to dementia guidelines through web-based training: by June 2013, more than 50 000 persons had participated in the training.
- An important area to strengthen guidance concerns patient safety and the use of guidelines to limit poly-pharmacy among elderly people. While there are in Sweden performance payments tied to reduction of inappropriate drug use among elderly people, it is not clear to what extent there are guidelines for professionals and care workers in LTC settings to follow.
- There are opportunities for developing non-clinical care guidelines. Like Sweden, most OECD countries have not developed non-

clinical guidelines for elderly care. Japan, Spain and France are the few exceptions. The Spanish Law 39/2006 encourages the development of "best practices" in nursing homes care. In France, best practices and protocols have been developed by national agencies such as ANESM (National Agency for Assessing LTC Organisations). In Japan, the development of practice guideline is not mandatory, but each provider and organisation produces their own internal guidelines and monitors their compliance by care workers (OECD, 2013).

Box 3.4. The Dementia Guidelines

The Swedish Dementia Guidelines were published in 2010 by the National Board of Health and Welfare (NBHW). They are directed to municipalities, primary care doctors and nurses and managed by the county councils. The dementia guidelines cover ten areas of care including prevention, living arrangements, medication and informal care givers. Within these ten areas, 157 items provide explanations for dealing with specific issues related to dementia. Recommendations are based on scientific evidence and are prioritised from 1 to 10, with 1 as the highest priority to orient the reader. All items have been developed and evaluated by expert groups during national and regional conferences. The guideline also includes 14 quality indicators developed by NBHW to be used to follow-up dementia care (Emilsson, 2013).

As in Sweden, dementia guidelines are emerging in other OECD countries. To mention a few examples:

- In Canada, the Coalition for Senior's Mental Health developed national, multidisciplinary guidelines on four key areas for the mental health of seniors, namely the assessment and treatment of delirium, depression, mood and behavioural symptoms in long-term care homes, and suicide risk and prevention of suicide (Conn et al., 2006).
- Ireland's National Dementia Education Project 2012 issued a guiding framework for education and awareness for person-centered dementia care in acute, residential, mental health and community care settings. The programme aims to assist staff working in dementia care to create an environment where people are cared for with dignity and a person-cenetred approach is fostered. It entails educational modules, and resources such as an information booklet and a CD, including to raise awareness of delirium (Health Service Executive, 2012).
- In the United Kingdom, NICE gives providers directions of how to manage information sharing with patients with dementia and their family (Cahill et al., 2012). The United States published a national Alzheimer's plan stressing the importance of specific care guidance for LTC providers.

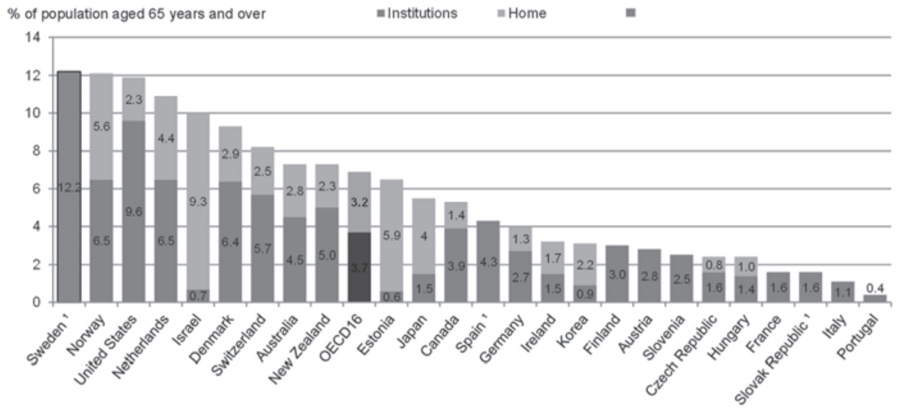
Box 3.5. The ProCare guide

The ProCare guide is a guideline referring mainly to elderly care but is also aimed at care workers in geriatric and health care. This guide was developed by the ProCare association, founded in 2001 by different health care entities related with elderly care. The guide states the requirements for meeting patients' physical, psychological, social and needs in sixteen areas that are summarised in point-form statements or quality requirements regarding geriatric health care, rehabilitation and personal care. These guidelines seek to provide discussion material at the workplace and to promote involvement, reflection, creative thinking and development of what and how things should be done (BRAVA Association).

Developing workforce competencies is an important component of quality assurance in LTC

Sweden has the highest relative number of LTC workers, at 130 LTC workers per 1 000 people aged 65 years old and over (Figure 3.8). However, the ratio of nurses to all long-term care workers (nurses and personal care workers) was, in 2011, among the lowest in all OECD countries, with only 5.5% of nurses among LTC staff, compared to an average share of 23.7 (Figure 3.9). Although many of the care tasks for the elderly do not require a high skills level, the growing complexity of care needs implies that the quality of care is increasingly a reflection of the level of the LTC workforce, and the lack of targeted qualifications for LTC staff can pose challenges to the quality of services (Castle, 2008; OECD, 2013).

Figure 3.8. Long-term care workers per 1 000 population aged 65 years old and over, 2011 or nearest year

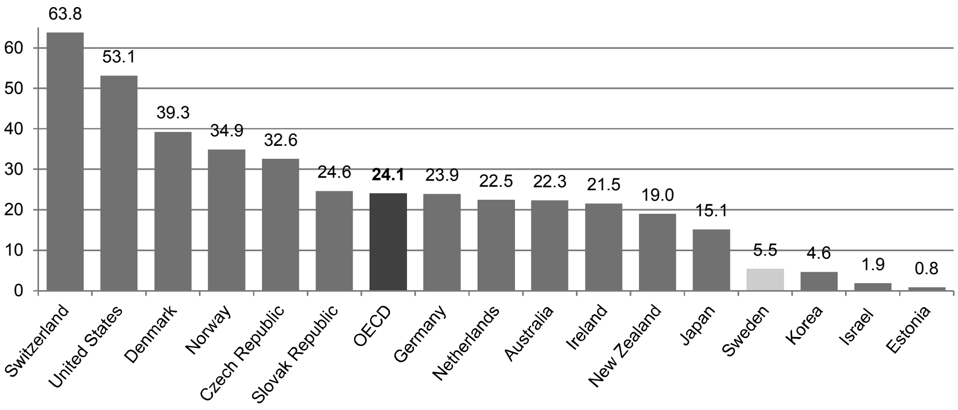


1. In Sweden, Spain and the Slovak Republic, it is not possible to distinguish LTC workers in institutions and at home.

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Figure 3.9. The ratio of nurses to all long-term care workers in Sweden was in 2011 among the lowest in all OECD countries

Share of nurses in relation to all long-term care workers (nurses and personal care workers), 2011 or nearest year



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

In Sweden, there are no requirements or qualification for LTC workers, nor are there national standards for workforce qualifications; it is often up to the municipality to establish a training programme. All employees must provide hands-on care, supervision and emotional support to older people with chronic illness and disabilities. These tasks may be challenging for workers who lack targeted qualification. LTC workers should also be able to use a computer, keep records and have discussions with relatives and other employees within the care sector, a challenge for those who have limited language skills (a majority of LTC workers in Sweden speak Swedish, but may have limited language skills) (SprakSam, 2012).

While the attractiveness of care jobs depends on a number of complex factors such as other work opportunities in the labour market, a positive development is that some initiatives are underway to upgrade the skills of LTC workers (see Box 3.6). For example, in 2012, the NBHW provided recommendations on staff qualifications for basic elderly care (to be equivalent to a three-year secondary school health care programme) and for specialised tasks such as dementia care, palliative care, mental illness, nutrition and rehabilitation. Furthermore, the proportion of assistant nurses working in special housing with secondary school training in health care has increased in recent years, from 76% in 2007 to 81% in 2010 (NBHW 2013). Participation by municipalities remains on a voluntary basis.

Sweden should consider ways to expand training initiatives to reach a larger share of LTC workers, including by mandating certain minimum levels. Some OECD countries regulate personal care workers' skills by setting minimum educational and training requirements, such as Japan, Spain, the United States (Home help Aide), Germany, Denmark and South Korea. Initiatives to upgrade skills of LTC workers already working in the sector have taken place in France, where social carers are required to complete 560 hours of practical training in addition to 504 hours of technical training. South Korea has a two-step approach requiring all potential workers to complete an initial 240 hour training, before entering a second 120 hour training. Denmark has a national curriculum for social and health care helpers and assistants lasting respectively one year and seven months and one year and eight month, which include both an education model and practical training (Colombo et al., 2011; OECD, 2013). In the United Kingdom, a recent review by the Department of Health (so-called Cavendish Review) proposes that all health care assistants and social care support workers should undergo the same basic training and get a standard "certificate of fundamental care" (*The Cavendish Review*, 2013).

Box 3.6. Swedish initiatives to increase LTC workforce qualifications

- In 2011, the Swedish Government began the *Omvårdnadslyftet* project, a four-year education initiative to improve LTC staff competencies. It focuses on LTC workers that have no formal education to meet the demands for more specialised skills. Municipalities can apply for state support to procure education courses that correspond to an upper-secondary level. The National Board of Health and Welfare has set the criteria for the content to be covered in the courses. In order to motivate municipalities to participate, a monetary reward is given at the end of the period to the municipalities that have raised competence levels to a certain degree. Approximately 10 000 people have commenced education within *Omvårdnadslyftet* since it was launched.
- The Swedish Government supports an education at university level for directors working in elderly care, offered over two years at four centres.
- The Swedish Association of Local Authorities and Regions have also initiated education programmes for directors working in elderly care, the *Leda för Resultat* and the *Ledningskraft* programmes.
- The *Språksam* Project is a good example of a training programme to overcome low language skills among LTC workers. The main objective of the project is to develop the competencies of employees at risk of labour market exclusion due to a lack of knowledge of Swedish. *SpråkSam* is delivered by the Stockholm Gerontology Research Centre of Stockholm County Council. It is delivered in 24 workplaces within elderly care and care of people with disabilities in the Järfälla, Lidingö, Solna, Sundbyberg, Södertälje and Stockholm municipalities. A second phase of this project (*ArbetSam*) will begin in 2013, and Swedish-speaking workers will be trained to help their non-Swedish speaking colleagues improve their language skills (SprakSam, 2012).

Expanding the LTC inspectorate function

Sweden monitoring and inspection model is about ensuring that minimum quality standards are met (e.g. that no abuses are committed to recipients). The model is, however, mostly reactive and largely based on complaints made by recipients.

Since 2010, the NBHW has been responsible for supervision, follow-up and evaluation of LTC services managed by municipalities and county councils. Prior to that, 21 County Administrative Boards were responsible for monitoring their jurisdiction. The shift in responsibility sought to ensure a uniform and systematic regulatory oversight over LTC services, although the NBHW is still in the process of developing adequate inspection infrastructure and the administrative, management or documentation system to allow for perform this role (Statskontoret 2011b). Moreover, there are no specific assessment criteria and common methods to base the inspectors' evaluations as yet.

Acknowledging these limitations, the Health and Social Inspectorate took over supervisory tasks in June 2013. The Inspectorate will inspect all facilities providing LTC, including home care, residential care, nursing homes and primary care as well as the pathways of care. This new supervisory arrangement combines inspection of health and social care facilities, which is expected to facilitate co-ordination. The new arrangement should allow the establishment of common quality standards, reducing local differences. It is expected that new internal management models, monitoring systems and procedures for case management adapted to deal with a large volume of cases would be set up. The challenge for the IHSCB is to have the administrative support systems in place since the start (Statskontoret, 2012a). Sweden should also ensure that the new system moves from reactive monitoring and response to identified deficiencies to more systematic inspections. By periodically checking adherence to desired quality levels, inspections can be powerful tools to encourage quality. The results of inspections and audits furnish important information regarding gaps in care services.

Notwithstanding the development of the inspection board, the Swedish Government could consider the possibility of introducing a system of accreditation of LTC services linked to required minimum quality standards. This would complement other quality assurance approaches such as those based on an inspectorate model. The thrust of accreditation is to embed improvement gradients into the health accreditation process through standards that are regularly revised by accreditation bodies to reflect notions of best practice. An advantage is that inspections can then be more specifically targeted to specific "critical" areas. Among OECD countries, inspections are a common mechanism for monitoring LTC quality and are usually linked to the accreditation processes. Inspections usually take place annually (e.g. Germany, Luxembourg, Portugal, Ontario Canada), between one to two years (United States, Korea), three years (Australia), five to seven years (France) (see Box 3.7).

Strengthening financial incentives for quality

Starting in 2010, the Swedish authorities set up performance-based incentives to encourage quality in elderly care. This is a change with respect to previous arrangements, where central government transfers to local governments were based on historical trends. In 2011, for example, the government allocated SEK 325 million to counties that demonstrated a statistically significant improvement in reducing unnecessary hospital based on two indicators: the reduction in the number of "unnecessary hospitalisations" of elderly people (based on selected diagnoses that should be possible to manage in out-patient and primary care settings, such as uncontrolled diabetes, COPD and asthma and care) and, the reduction in the number of elderly people being re-hospitalised within 30 days after hospital discharge.

Another incentive seeks to reduce the inappropriate use of drugs. Medication use among the elderly has increased over the last 20 years and nearly 30% of emergency admissions of older people in hospitals are linked to drug-related problems. Monetary rewards are given to counties that reduce the use of inappropriate drugs, reduce the inappropriate combinations of drugs and the use of psychotropic drugs among elderly people in institutional care.

As mentioned already, there are also incentives payments to municipalities for reporting individuals in the *Dementia* and *Senior Alert Registers*. The NBHW will allocate SEK 25 million to those municipalities that, in partnership with local authorities, develop and try models for implementing national guidelines in 2012-13.

For all performance-based incentives, the improvement standards required to receive payment incentives are defined by SALAR and NBWH. Counties that meet target objectives and receive funds share the payment with the municipalities (commonly 70% of the funds are paid to municipalities and 30% to the county council).

While there is much experimentation with pay for performance arrangements in health care around the world, there is little empirical evidence that pay for performance programmes increase quality in LTC services (OECD, 2013). Concerns have been raised that incentives focus only particular services, that having providers' self-report performance data might lead to dubious results, and that providers might be tempted to select users that will increase chances of achieving a good results (Colombo et al., 2011; OECD, 2013). Credible performance measures addressing a broad range of quality and quality of life indicators in LTC are under development (Arling et al., 2009).

Still, the experience of Sweden is a remarkable example of how relatively small performance incentives and efforts to link them to quality indicators can, despite the challenges, motivate decentralised level of governments to improve reporting and to seek ways to address the most blatant variation in quality of care. Despite its difficulties, there are no reasons why these payment incentives should not give good results in elderly care, if only starting by motivating higher reporting of data by providers. That said, it will be important to address challenges, some of which have also been identified by the Agency for Public Management in an evaluation of the scheme:

- *There is a need to motivate individual providers not simply counties or municipalities*. Payments do not always make their way to the organisations that generated the improvement, lowering the motivation to perform well or to keep data records as proof of the improvements.
- *A focus on how to reach/incentivise certain groups of providers*, such as smaller providers, those in more remote areas or private providers, might be important.
- *The way the payment is calculated should be made more transparent*, and the data in which the performance-based compensation relies should be validated.
- *Routines for administering the payment might need revision*. For example, standard routines for administrating payments, responsibility for calculating the size of payments, for putting together basic data for compensation may be needed (Statskontoret, 2011a).

3.5. Pursuing initiatives incentivising integration

In the final stages of life, most people are exposed to a growing number of health problems, generating a substantial demand for health and social care (Meinow, 2011, Lennartsson and Heimerson, 2012). This group of people have functional and cognitive limitations and are dependent of help from multiple caregivers, across the health and social care sectors. This results in a substantial need for on-going collaboration between different medical care specialties, as well as across professional and organisational boundaries. Across countries, major deficits exist in co-ordinating the necessary interventions for those suffering from concurrent illnesses (Fratiglioni and von Straus, 2007; OECD, 2013). There is hope that the benefits of effective integration would be most evident for this group of people and those with complex care needs.

Sweden faces the challenge of bringing a holistic approach to elderly care management. Almost 20 years after the Elderly Reform Bill (1992) that shifted LTC administration from county councils to municipalities, the division of responsibility for LTC is well established in Sweden, but the integration between health (managed by counties) and social care (managed by municipalities) remains an important challenge (Fukushima et al., 2010) (see also Chapter 2).

This section discusses the challenges of integration in Sweden elderly care, making reference to local projects that have shown promising results in promoting integration. While international experience suggests the need for caution regarding the financial benefits of integration, there are encouraging signs that this helps improving quality of care and quality of life. Four key areas for the future are:

- reviewing the legal framework set by the various health and social care acts to identify any regulatory blocks to integration
- continuing to use financial incentives for reducing (unnecessary) hospitalisation and re-hospitalisations of frail and dependent elderly people
- encouraging data integration across health and social care, multidisciplinary teamwork and joint purchasing or other innovative organisation forms (such as intermediate care)
- encouraging systematic evaluation of local examples of integration and inclusion in assessment reports to be published by central authorities, including public celebration of good examples.

Reconciling the legal frameworks of health and social care

The health and social care sectors have different legislative frameworks, and defer to different political and administrative units (Wadmann et al., 2009). Health care is under the responsibility of county councils and governed by the Health Services Act, while social care is under the responsibility of municipalities and governed by the Social Care Act.

Decentralisation and these administrative divisions introduce of necessity some degree of fragmentation.

There are significant differences in the legal framework for health and social care. These differences include the language used and the degree of specificity in the legislation: although Swedish legislation traditionally has detailed laws and instructions, the Elderly Reform provides general recommendations and sporadic regulations; details are left to be resolved at the local level. This is because the underlying premise in the reform is to rely on competitive, decentralised self-regulating systems with reduced central governance (Andersson and Karlberg, 2000). The lack of detail in the social care legislation can produce misalignment between professionals across health and social care, as they have competing goals and different definitions of quality. For example, it is not always clear where the responsibilities for medical treatment end and where social care begins in both home and institutional settings. The lack of a clear definition and explicit accountability rules can lead to co-operation conflicts and attempts by county councils and municipalities to transfer responsibilities and costs to one another. This can in turn result in frail dependent elderly individuals receiving insufficient or delayed care (Fukushima et al., 2010). A consequence can be a high number of dependent people being hospitalised when more effective co-ordination with the primary care and home (health) care system could have prevented this. Another consequence is the difficulty in scaling up or event continuing some of the useful local projects promoting integration.

This suggests a need for reconciling some of the differences between the two legal frameworks and encouraging integration. A first step would be by delivering a careful review of the differences in the health and social care acts legal frame to identify and specifically address barriers to integration.

Encouraging integration of health and social care data

Integration of health and social care data sources helps to draw a comprehensive picture of care management (ALCOVE, 2013). People involved in the provision of services towards the elderly, require a uniform plan of care to facilitate continuity across settings. For this to happen, accessible patient records that contains the patient's medical problems, medication regimens, allergies, baseline physical and cognitive function, and contact information for all professionals and caregivers are needed (Coleman, 2003). This, in term, requires interoperable electronic health records and health information exchanges enabling medical records to be portable across health and social care settings. Two key ingredients for success are strong information technology infrastructures and data portability (OECD, 2013).

In Sweden, the flow of information from the health sector to the social sector barely exists. The medical sector keeps detailed patient records that are not shared with the social sector. Health national laws on patient privacy restrict a shared client record system and municipalities often do not have the necessary equipment and capacity to keep comprehensive patient-level records and track patients across different care settings. Although a data collection infrastructure in the health sector exists, Sweden is also a long way from having a cohesive information system even for health care, which makes integration with social care even more challenging.

While all OECD countries are struggling to integrate health and social care information systems, Sweden could start this important journey with the following steps:

- standardising medical and social care records and improving the information technology infrastructures
- linking medical care records to hospital, community and social care records
- taking advantage of the existence of a unique identification number
- integrating the different registries to follow elderly patients through and then expand to other social care settings
- training personnel to be able to track, read and interpret the patients' medical and social care record.

Linking patient data using has shown the potential for success through the national LTC registers (the Swedish Dementia Registry, Swedish Registry on Behaviour and Psychiatric Symptoms in Dementia, Senior Alert Registry and the Palliative Registry). These experiences can be extended to cover a wider group of elderly and can be used by more municipalities and services providers. Box 3.7 provides examples of information integration initiatives in other OECD countries.

Box 3.7. Initiatives from OECD countries to promote the integration of health and social care information

The Australian Institute of Health and Welfare explored care transitions for older people with dementia, cardiovascular disease, arthritis and musculoskeletal conditions. Records for all people aged 65 and older who were assessed under the Aged Care Assessment Programme were linked to data for six major aged care programmes and to mortality data over a four-year period. The linked data enabled examination of care pathways and the factors influencing different care paths. Of particular interest were the entry into and the time to entry into residential care and how this may have been influenced by the use of community care (AIHW, 2011).

In Torbay, a small English community, Torbay Care Trust brings together commissioning and provision of adult social care and community health services. The Trust records users' NHS number and links health and social care records. It has linked hospital inpatient, outpatient with community services activity and adult social care services and is now linking with GP practice records. The information has been used to support patients at home and reduce hospital bed use, emergency bed days, delayed transfers of care and costly care home placements (Jonas et al., 2012).

Another example is the Consumer Assessment, Referral and Enrollment (CARE) tool implemented is the San Francisco Department of Aging and Adult Services (DAAS). CARE is an Internet-based care management programme that enables providers and agencies to exchange information and co-ordinate care management. CARE provides a single point of entry for all DAAS services. Once a patient has been entered into CARE, the tool can automate referrals to other relevant services within the ageing network and allow programmes serving the same individual to share assessments, care plans, and progress notes (Coleman, 2003).

Some OECD countries have successfully launched initiatives to promote the integration of health and social care information. Many use standardised assessment instruments integrated into the information platform. Canada, Belgium, Iceland and the United States have adopted the InterRAI system. On Belgium participating hospitals, nursing homes and care organisations have access to the BelRAI web application (OECD, 2013).

Using financial incentives to encourage integration

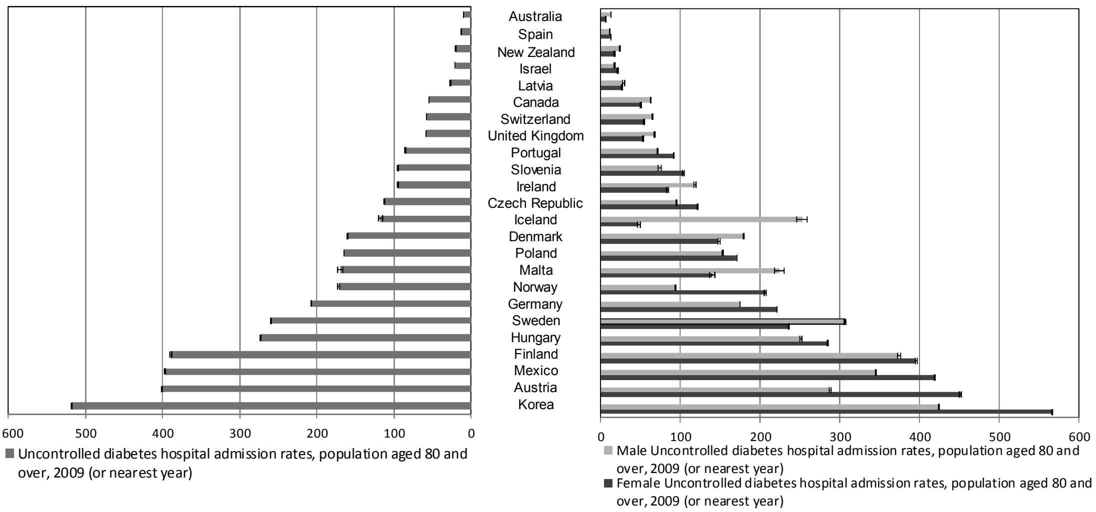
Sweden makes significant use of financial incentives to steer change. Since 1992, municipalities in Sweden have been required to arrange care for dependants after treatment in acute and geriatric hospitals, in an effort to reduce utilisation of health services. By making local governments financially responsible for the cost of patients whose acute care treatment has been completed, municipalities have strong incentives to take care of elderly people upon discharge from hospitals (e.g. through expanding housing for the elderly, special housing, round the clock care services, home-care service, etc.).

Over the years, this led to shorter length of stays (5.5 days in 2011, the shortest in the OECD after Denmark, Turkey and Mexico, and well below the

OECD average of eight days) and a reduction in so-called social hospitalisation. OECD data demonstrate that avoidable hospitalisation in the elderly population for respiratory diseases is low by OECD standards, but relatively high for uncontrolled diabetes, suggesting room for improvement (Figure 3.10). Elder care services in general are now focusing their efforts on reducing or delaying hospital admissions (Regeringskansliet, 2012). There is little evidence available to date, however, on the impact of such initiatives.

Given the important results achieved through the use of financial incentives, it is clear that continuing in this direction is worthwhile pursing. That said, this needs to be complemented by other non-financial incentives and encouragement. The shortened length of stay in acute hospital care increases care-load in nursing homes and there seems to be a shortage of intermediate care facilities to better manage the transitions between acute, rehabilitation, and LTC. Rehabilitation for example is primarily a function of municipalities, but there is little co-operation with county councils managing primary care. Only about half of the municipalities have taken responsibilities for home health care. Among those municipalities, there is little evaluation of the extent that they have been successful in improving quality of care, reduced unnecessary expenditures and improved quality of life of elderly.

Figure 3.10. Uncontrolled diabetes hospital admission rates, population aged 80 years old and over, 2009 or nearest year



Source: OECD (2013) based on *OECD Health Statistics 2011,* OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Encouraging multidisciplinary teams and service integration

Integrated care pertains both to professional integration (such as through use of joint guidelines or multidisciplinary teams) as well as service integration (such as through better managing care transitions or joint health social care planning). There are a number of interesting examples already implemented at local level in Sweden.

- Municipalities around Lidköping started a common political board and are delivering co-ordinated care for the most fragile elderly. To accomplish this goal, staff from different professional and institutional backgrounds work in networks to provide services such as day care medical rehabilitation; geriatric day care; and occupational therapeutic and physiotherapeutic work in people's own homes. Project groups have also been established to collectively examine issues of terminal caring, psychiatry and more recently the management of long-term illnesses such as dementia, diabetes and heart related diseases. By developing clear objectives, a common documentation system, system competence measures and flexible working practices between professionals they were able to significantly reduce hospitalisation rates among the elderly (Godwin et al., 2008).
- Gävle municipality establishes joint primary care/municipality elderly care teams, constituted by people from councils and municipalities. They create joint plans for elderly persons upon discharge from the hospitals.
- Jönköping county created an imaginary elderly person (Esther) and tracked her movement along the care spectrum to identify and work on improvements as she flowed through the care system (Baker et al., 2008). With this imaginary person, Jönköping was able to identify decision points relevant to the needs of patients requiring several supports. There has been a significant improvement in the co-ordination of emergency and home care. Visiting nurses work with emergency room professionals to identify why patients visited the emergency rooms and what home-based care might reduce the reliance of emergency care among the elderly. Jönköping is now focusing in improving home tracking, educating patients in self-management, providing better information to families, establishing more frequent phone consultations and better chronic pain management (Lawrence, 2003).
- Södertälje municipality succeeded in joining health and municipality personnel to care for people with mental health problems (see Box 3.8).

Box 3.8. Södertälje's "consortium"

The Swedish municipality of Sodertalje established a shared care model for people with mental health problems. The initiative (the "consortium") achieved a sustained close co-operation and a shared treatment model between the county psychiatry clinic and the municipal social services. About half of the patients served were diagnosed with schizophrenia, with some diagnosed with schizoaffective psychosis or acute psychosis. The project combines the following integration initiatives:

- new care co-ordination arrangements including joint care co-ordinators, care planning systems and communication arrangements for the secure exchange of client information
- three new shared rehabilitation centres, each with a joint team of health and municipality personnel
- a new joint addiction and outpatient psychosis team
- a set of operational and higher level joint management groups.

The work towards establishing this consortium and shared model of care began in 1994, and its establishment took to 2004, reflecting that the accomplishment of integrated systems, even at the local level, is a long-term project that takes time to consolidate and see results. The process was long and overcame many difficulties and obstacles, such as:

- the need to refer many items for agreement to the higher levels of two organisations made the decision-making process slow
- the different procedures and policies of the two organisations reflected two ways of working
- the rules of confidentiality about transfer of information between health and social care and a hospital-centered model of care held by many in psychiatry and the county
- a resistance to sharing care and negotiating client care decisions with practitioners in the municipality.

Source: Hansson, J. et al. (2012), "Case Study of How Successful Co-ordination Was Achieved Between a Mental Health and Social Care Service in Sweden", *International Journal of Health Planning and Management*, Vol. 27, pp. 132-145.

These initiatives, albeit small, identify some important elements of success to foster integration:

- the importance of the regular contact between medical practitioners and institutional care. Contractual arrangements that facilitate regular contact and "walk-rounds" by GPs, nurses or other medical professionals in nursing homes and home settings facilitate integration
- joint clinical and care guidelines helping to co-ordinate care through different pathways and reduce avoidable medical and care variations. With the exception of dementia care guidelines, available national guidelines that target elderly people care do not span to

social care and are not specifically address to LTC. Particular attention needs to go to guidance for co-ordinating complex needs once they have been discharged from the hospital

- joint care co-ordinators, care planning systems and communication arrangements; preliminary results from an evaluation of 19 local integrated care projects in Sweden by the Aging Research Center (ARC) over the 2011-14 period highlights that different types of case management are used to detect "elderly persons at risk"; a successful initiative are mobile teams providing proactive, early interventions at home instead of the person having to go to hospital
- the need for specialised organisations to meet the needs of elderly people with complex health problems and intermediate care services, coupled to appropriate quality assurance systems.

Useful examples of these types of integration can be found in several OECD countries (Box 3.9).

Box 3.9. Useful example of professional and service integration in other OECD countries

In France, the Service Intégré de Soins à Domicile co-ordinates the distribution of tasks among health and social care professionals for home care. In Iceland, doctors are on-call for emergencies or visit nursing homes two to five times a week. Most nursing homes provide physiotherapy and some occupational therapy. In England, as an effort to improve the continuity of care and decrease fragmentation across care settings, a new breed of health care professional has emerged, the geriatric nurse practitioner (GNP). GNPs usually work under the supervision of physicians, but opportunities are developing for them to establish a significant role as independent practitioners who can provide most of the spectrum of primary care in a context that emphasizes health maintenance.

Denmark, is implementing a series of strategies to follow elderly patients once they are discharged from hospitals through preventative visits at the home for all older persons, contracts between municipalities and hospitals about discharge procedures, meetings between home nurses and hospital staff (Colmorten et al., 2003 in Leichsenring, 2003). In the United States (in the state of Colorado), Care Transition Coaching interventions encourage management of care transitions, self-care, and improve communication across care settings have shown encouraging reductions in rates of re-hospitalisation by coaching frail elderly with chronic conditions and their caregivers to ensure that their needs are met during care transitions (Coleman et al., 2006).

Norway is settings up intermediate care facilities of the type that have emerged in coupled by quality assurance mechanisms (OECD, forthcoming). These have included, for example, urgent care centres appended to hospitals, intended particularly for patients with known diagnoses suffering from an acute exacerbation; social care beds, where frail individuals can admit themselves for a few days if they feel they are not coping at home alone; using beds in nursing homes to receive discharged patients for a short spell of recuperation/rehabilitation prior to home discharge; and setting up new, dedicated rehabilitation facilities.

Fostering opportunities for pooling budgets and organisational integration

A further degree of integration consists in merging organisational and financial boundaries through joint purchasing, pooled budgeting, single payments systems or bundling across health and social care. This is the most complex level of integration, but one that encourages continuity of care and shares financial risk across different levels of government or organisational units.

Sweden faces several challenges for this type of integration including legal frameworks, a large number of municipalities with a high degree of autonomy and reluctance by professionals to accept changes in their practices (Sandlund, 2008). Despite these difficulties, certain local efforts have succeeded in promoting organisational and financial integration by creating an administrative structure that combines the municipal and the county levels and co-ordinates the organisation and financing of elderly care service. The example of the TioHundra project in Nortellje is provided in Box 3.10.

Sweden could also look at examples from other countries. In the United States, the PACE programme proves integrated health and social care for poor elderly people with complex care needs by integrating day care, prevention and support care under a unique platform. The programme uses proactive case management, and pays providers capitated payments (Colombo et al., 2011). Also in the United States, social HMOs are insurance models spanning primary care and LTC that use capitated payments and active management of care (Thomas et al., 2010). Some outcomes of these initiatives are promising (e.g. reduced hospitalisation and lower risk of long-term institutionalisation), although set up costs can be high (OECD, 2013). In Belgium, nursing and ADL assistance are integrated into health coverage through the social health insurer INAMI. Health and social care services for home care have been integrated through so-called *Service Intégré de Soins à Domicile* (as in France). Another form of integration is through partnerships across providers to monitor spending and performance, although without pooled funding or joint financial responsibility, it can be difficult to achieve the desired results (OECD, 2013).

The main lessons that can be drawn from these examples is that this form of integration requires strong upfront investment and continued political commitment.

Box 3.10. TioHundra project in Norrtälje

The municipality of Nortellje implemented joint planning and purchasing of services for old people (the TioHundra project) which led to a reduction in hospital admissions and efficiency gains for psychiatric and elderly care. The planning and preparation of this project started in 2004 and the project was based in three components: a) an integrated health and social care organisation, the TioHundra Administration, constituted as a public company providing the services; b) a joint political governing board, with members from the municipality and the county, responsible for both health and social care and c) "TioHundra Fovaltningen", the administrative organisation that co-ordinates the financing structures. In 2009, further structural and other organisational changes were made at the clinical "micro level" to improve clinical care co-ordination. These recent activities included:

- the development of one manager for both geriatrics and elderly care
- the start of a joint individual care planning, focusing on preventive care
- the start of a new more co-ordinated patient pathway for stroke patients for their entire care episode.

Some of the challenges encountered by the project were the different occupational cultures, the lack of willingness to co-operate because of perception of too much extra time needed for co-ordination and the lack of an integrated information system across the social and health care organisations. Another difficulty was the lack of clear and direct incentives to promote co-ordination, apart from possible but uncertain savings through improved care co-ordination resulting from faster hospital discharge and reduced avoidable admissions.

Source: Øvretveit, J., J. Hansson and M. Brommels (2010), "An integrated health and social care organisation in Sweden: creation and structure of a unique local public health and social care system", *Health Policy*, Vol. 97, pp. 113-121.

3.6. Conclusions

Sweden is regarded internationally as a best practice example for elderly care. This is comprehensive (both with regards to the services provided and the human resource investment) and highly accessible (a high share of public spending in relation to GDP and little private financing required by individuals). Yet, there is surprisingly little measurement of outcomes of long-term care services and few standards of care. Elderly people in Sweden have fewer functional limitations than in most other OECD countries, and also the second highest level of healthy life years at age 65 in the European Union. Although the link between long-term care services and functional limitations is hard to ascertain in any country, it is important for policy makers to measure that elderly care services are safe, effective, and centred around the people receiving care. While Sweden is making significant progress in measurement of quality in long-term care, for example by strengthening the registries covering frail elderly people, it is still difficult to say whether better outcomes of care could be achieved for the same high level of spending on LTC, equivalent to 3.6% of GPD in 2011. Other OECD countries, including the United States, Canada, the Netherlands, Germany and England have a better developed quality infrastructure for LTC, especially for institutional care.

Sweden is making significant efforts to address these shortcomings. For example, Sweden has linked budget transfers from the Ministry of Health to municipalities to measures of LTC outcomes, such as reductions in avoidable hospitalisations of elderly people and unsafe use of medications. Through the same incentive mechanism, Sweden is encouraging the collection of data on other indicators such as dementia care, elderly falls or malnutrition that are contained in some of its impressive clinical registries.

Sweden also motivates underperforming local governments to do better through public disclosure of indicators of elderly care which are being added to its *Quality and Efficiency* benchmarking reports across counties. This has been a powerful quality-improvement tool employed in health care, since local governments appearing at the bottom of the ranking have strong motivations to improve. Sweden is reforming its inspectorate model, too, by extending its role over LTC facilities. There are also remarkable local innovations with care integration, such as Södertälje consortium involving personnel from county and municipalities to care for people with mental health problems or the joint purchasing project in Norrtälje. These are just a few of the good example. These schemes and initiatives ought to continue, and be thoroughly evaluated, over the coming years.

Despite these admirable efforts, there remains an unfinished agenda that Sweden should address without delay. This includes a need for:

- a more holistic and shared vision of quality assurance in long-term care services, including a shared accountability framework
- the establishment of a solid information infrastructure on quality and performance of LTC. This may first require addressing legal issues (such as privacy and differences in the health and social care acts), as well as technical issues (such as standardising health and social care records, building capacity to collect the data). Progressing from what exists already (that is, the four quality registries covering elderly care and a unique patient identifier), infrastructure needs to expand coverage and linkages (across registries and between social, GP and hospital records for example)
- an expansion of the open benchmarking approach exemplified in the *Quality and Efficiency* reports, including expansion of the

performance incentives for local governments. This is likely to involve gradual inclusion of more elderly care indicators, by evaluation of findings and iterative fine-tuning

- more decisive steps towards a quality assurance model for LTC. There is scope for considering standardised assessment instruments to collect quality data, monitor deviations, and derive protocols of practice, as done in several other OECD countries. Additionally, there is scope for enlarging existing clinical guidelines to include social care (as done for the dementia care guidelines) and co-morbidities affecting the elderly. Finally, there is a clear need for minimum competency standards for care workers, including in home care settings
- continued emphasis on care co-ordination, as an important outcome of elderly care. Important elements would include facilitating sharing of records across health and social care, addressing inconsistencies in the legal frameworks, encouraging innovation and evaluation of joint planning and purchasing pilots across municipalities and counties.

Addressing these issues will help Sweden strengthen the building blocks of a LTC governance model based on transparency, as well as appropriate incentives and competition across local authorities and providers. The need to move towards a stronger quality measurement and assurance model is clearly not unique to Sweden. Several other OECD countries are finding this a challenging endeavour. Sweden is in a uniquely strong position, however, to take on this challenge of setting a model for quality assurance in LTC and pioneering its implementation.

Notes

1 Data on beds in institutions in the OECD include also beds for people with functional impairments younger than 65 years, beds in short-term institutional care, and beds in geriatric clinics. Other data reported in Swedish publications focus on a narrower definition that only include municipal institutional beds for older people

2. This phenomenon is common to other Nordic Countries. Studies have found that users of social services in a free choice system find it difficult to understand information about the system itself and about the providers (Edebalk and Svensson, 2005).

3. The Elderly Guide is available at http://aldreguiden.socialstyrelsen.se.

4. RKA's mission is to help monitoring local governments' activities and encourage comparisons across counties and municipalities.

5. KOLADA is available at http://www.kolada.se.

6. More information on the Older Direct initiative is available at: www.stockholm.se/FamiljOmsorg/Aldreomsorg/Ring-Aldre-direkt/.

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Chapter 4

Care after hip fracture and stroke in Sweden

The degree to which a health system routinely provides high quality health care after a stroke or hip fracture directly reflects its capacity to provide a complex and tailored array of health and social care services in the face of sudden and unexpected disability.

This chapter assesses how well Swedish health care meets such a challenge. Sweden's national standards for stroke care, and in particular its monitoring framework, are amongst the most detailed and extensive in the world. In contrast, quality initiatives for care after hip fracture are less advanced – no national standards or guidelines for care exist. For both conditions, however, the quality architecture is predominantly concerned with the acute phase of care – there is a distinct lack of guidance or quality monitoring for on-going care once a patient has been discharged, which is happening earlier and earlier in the patient pathway.

There are a number of ways in which Sweden can strengthen the quality of health and social care provided after a stroke or hip fracture. These include developing joint health and social care standards and guidelines, ensuring that quality monitoring frameworks reflect changes in how services are organised and provided, using community rehabilitation resources more effectively and devoting particular attention to secondary prevention.

4.1. Introduction

The final chapter in this quality review examines the quality of care after stroke and hip fracture. Both conditions represent a sudden and unexpected loss of health, independence and well-being and will trigger a complex set of health and social care needs. These must be met in a timely, co-ordinated and personalised manner if an individual is to regain as much of her former functional ability as possible. The chapter places particular emphasis on post-acute care after hospital discharge. This is in order to complement earlier chapters on Sweden's general quality architecture, on primary care and on long-term care, each of which had a particular emphasis on care for the elderly. This chapter can be seen as a case-study which seeks to illustrate the issues raised in earlier chapters.

4.2. The burden of stroke and hip fracture in Sweden

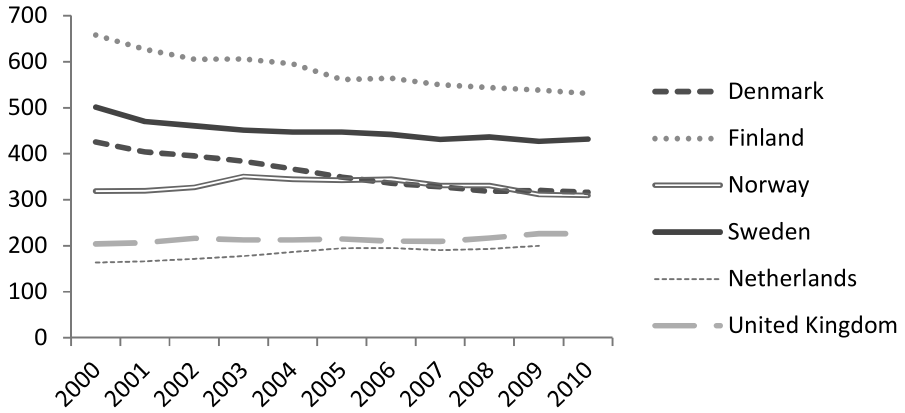
In 20 years' time, one in four of the Swedish population will be aged over 65. Although most of these individuals will be healthy, increasing numbers of strokes and hip fractures imply an ever greater burden on health and social care services going forward. Hence, high quality services which meet people's needs are important. Efficiency is also important, and it is known that high quality care, that is effective, free from errors and patient-centered reduces costs in the long term.

The degree to which a health system routinely provides high quality health care after a hip fracture or stroke is a good index of how well a system can respond in an effective, safe and personalised way to a sudden and unexpected change in an individual's demand for health and social care. This is one of the greatest challenges that health and social care systems face, whether at local service level or national strategic level.

Stroke, although decreasing in incidence, remains a significant burden on the Swedish health system as well as wider society

About 30 000 patients in Sweden suffer a stroke annually, of which an estimated 23 000 are first-ever events. As Figure 4.1 shows, age-standardised rates of hospital discharge for stroke, a measure of incidence, are slowly declining in Sweden but remain significantly higher than some other countries. Declining incidence in high income countries is a well-recognised phenomenon, due to better management of risk factors such as high blood pressure and reduced smoking (WHO, 2004). Nevertheless, ageing populations means that the absolute burden of ill-health and disability caused by stroke may not decline substantially.

Figure 4.1. Age-standardised discharge rates per 100 000 population for cerebrovascular diseases in selected OECD countries, 2000-10



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

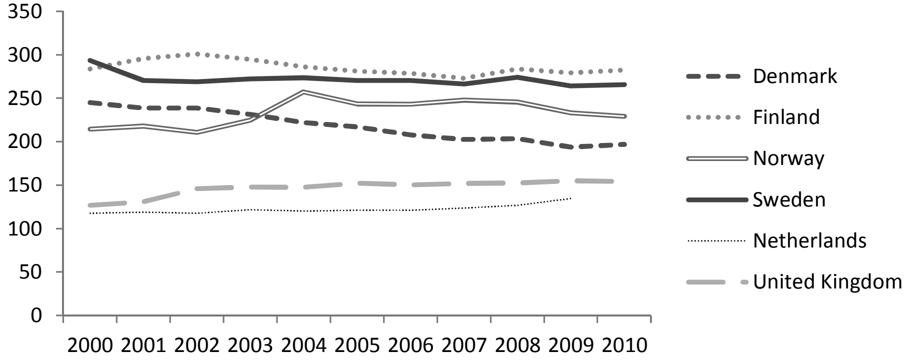
Stroke is the third leading cause of death in Sweden. For those who survive, about half are left with some degree of physical or cognitive impairment and may need substantial support to manage tasks of daily life, from both professional caregivers and family or friends (di Carlo, 2009). After a period of intensive hospital-based care, aiming to minimise neurological damage as rapidly and as far as possible, recovery most often begins with a phase of rehabilitation. Together, stroke care consumes more bed days in Sweden than any other somatic condition – around a million per year in the hospital sector and substantially more in nursing or assisted-living facilities.

In recent estimations, Sweden spends 2% of total health care expenditure on cerebrovascular disease (in line with the EU average); non-health care costs are estimated to include SEK 1 500 million (EUR 180 million) on production losses and SEK 1 400 million (EUR 167 million) on informal care (Nichols et al., 2012). The total estimated cost of stroke to society in Sweden has been estimated at SEK 14 billion (EUR 1.5 billion) per year (Socialstyrelsen, 2011).

In contrast, the incidence of hip fracture in Sweden shows little sign of decline and is amongst the highest in the world

As Figure 4.2 shows, age-standardised hospital discharge rates for fractured neck of femur are higher in Scandinavian countries than elsewhere in Europe. Even amongst Scandinavian neighbours, however, Sweden has a relatively high incidence of hip fracture. This has been observed in other international comparisons (Ström et al., 2011) and may be due to reduced sun exposure at northern latitudes, which supports the body in synthesising vitamin D and thereby adequately mineralising bone. Detailed analysis of the national trend in incidence rates undertaken by Nilson et al. (2013) finds that incidence rates have decreased for all age- and sex-specific groups, with the largest changes in the younger age groups and among women. The absolute number of hip fractures among the elderly in Sweden, however, has largely remained constant over recent decades.

Figure 4.2. Age-standardised discharge per 100 000 population for fracture of femur in selected OECD countries, 2000-10



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Approximately 85% of all hip fractures occur in individuals aged ≥65 years (Braithwaite et al*.,* 2003). Between 18% and 33% of older hip fracture patients die within one year of their fracture. Amongst survivors, however, fractures of the hip are associated with a greater loss of independence, morbidity and mortality than any other type of fracture (Boonen and Singer, 2008). Many of those living independently before their fracture do not return to their pre-fracture level of independent living a year after fracture, including the ability to walk without assistance (Magaziner et al*.,* 2003).

In Sweden, annual health care costs associated with fractures are estimated at SEK 5 639 million (EUR 610 million), four-fifths of which is accounted for by hip fractures – around 3% of the total health care costs. Most costs are due to community care (66% of the total annual cost), followed by medical care costs (31%), informal care

(2%) and indirect costs (1%). Including lost productivity and quality of life costs increases costs by around three-fold (Bergström et al.*,* 2007)

4.3. Characteristics of high quality care after stroke or hip fracture

Although this chapter looks specifically at the quality of health care in Sweden *after* the acute hospital phase for these two conditions, focussing on rehabilitation and secondary prevention, the importance of other phases of care should be mentioned. The first few hours of hospital care, when diagnosis, risk stratification and stabilisation are undertaken, are critical to minimise the extent of irreversible damage. Equally important, however, is primary prevention to prevent strokes and hip fractures from happening in the first place: management of blood pressure, lipids, smoking, overweight and diabetic or pre-diabetic states in the case of stroke; and reducing the risk of falls and managing osteoporosis in the case of hip fracture.

Rehabilitation should start early, be individualised, multidisciplinary and goal oriented

Once the acute phase of a stroke or hip fracture is no longer evolving, the rehabilitative phase of care can begin, aiming to restore as fully as possible the patient's ability to move, self-care, communicate and participate in society. Legg et al. (2007) pooling results from several studies in a systematic review of occupational therapy after a stroke report a relatively low "number needed to treat" (NNT)[1] for this particular form of therapy – around ten – to avoid deterioration or dependency in the activities of daily living. Similarly, Halbert et al. (2007) find that the NNT after hip fracture to avoid death or disability is 24.

Individualised and goal-oriented rehabilitation is self-evidently necessary, given patients will differ in the severity of their stroke or fracture, their prior level of function, their support network and dependents, and their goals. Rehabilitation needs should be assessed quickly and rehabilitation should start as soon as the patient is medically stable and physically and cognitively able to participate. Evidence and several international guidelines emphasise the need for a team of specialists to be involved, including a rehabilitation physician, specialist rehabilitation nurse, physiotherapist, occupational therapist and social worker (Mak et al., 2010; Cameron et al., 2005; Halbert et al., 2007). In the case of stroke, input from a speech and language therapist may also be necessary. It is well recognised that depression and anxiety may follow stroke and that support from a clinical psychologist can be beneficial. Using data from the Swedish quality register for hip fracture (described in more detail in Section 4.4), Hommel et al. (2012) demonstrate that anxiety about returning home and resuming usual activities is also prevalent in this patient group.

It is important to note that the mere presence of multiple rehabilitation specialists should not be assumed to lead to effective care. Indeed, one systematic review of rehabilitation after hip fracture found weak or conflicting evidence for the benefit of multidisciplinary care (Chudyk et al., 2009). Similarly, care pathways –which are often established in an attempt to effectively integrated multidisciplinary care- may have a limited role beyond the acute phase. A systematic review of their benefit after stroke found that, although integrated care pathways appear useful for goal-setting, the variable and unpredictable trajectories of patients' recovery during rehabilitation renders their utility less evident (Allen and Rixson, 2008). Multiple specialists must co-ordinate effectively to identify and meet a patient's individual and evolving needs. To maximise the effectiveness of this complex array of services working together, the Stroke Unit Triallist's Collaboration suggest that co-ordination is achieved via five key factors, namely: weekly team meetings, nursing integrated into multidisciplinary team, carers routinely involved in rehabilitation and team meetings, provision of carer information and training and support for staff to develop a specialist interest in rehabilitation (Cochrane Database of Systematic Reviews, 2007).

Early supported discharge may have benefits in selected patients

Rehabilitation most often takes place on the acute hospital ward or on rehabilitation units. Recently, however, interest has developed of offering patients with relatively mild loss of function the possibility of early discharge from the acute setting with continued rehabilitation at home. To be eligible for early discharge, patients should meet minimum criteria such as being medically stable, cognitively able to continue with rehabilitation and able to mobilise short distances safely, such as moving from the bed to a chair without assistance. A specialist multidisciplinary team should take on-going responsibility for the patient's recovery and ensure adequate, regular face to face contact until the agreed rehabilitation goals have been met.

There is increasing evidence that rehabilitation in a person's own home is associated with greater patient satisfaction and as good or better functional recovery. Langhorne et al. (2007) in a systematic review of randomised trials of early supported discharge after a stroke finds reduced odds of death or dependency equivalent to five fewer such outcomes per 100 patients treated. Chudyk et al. (2009) in a systematic review of hip fracture rehabilitation practices finds supportive evidence for improved recovery in patients offered rehabilitation in their own home. Notably, there was also some evidence that this need not be resource intensive – in one study; three face-to-face contacts a week were as effective as six.

Home rehabilitation services may be more difficult to organise in rural areas, however, and it remains unclear which components of multidisciplinary rehabilitation are most determinant of effective care. It is also important to note that home based services have not been shown to be cost-saving, both within the specific setting of Swedish post-stroke services (Von Koch et al., 2001) and for a mix of medical and surgical conditions in elderly patients more broadly (Shepperd et al., 2001).

Effective secondary prevention is necessary to prevent recurrent strokes or fractures

Amongst stroke patients, the risk of a further stroke is around 30% at five years, around nine times higher than the general population; the risk of other cardiovascular events such as a heart attack is also greatly increased (Burn et al., 1994; Touze et al., 2005). Recurrent events are more likely to be fatal than a patient’s first stroke (Rothwell, 2005). Several interventions, however, have been shown to be effective in reducing the risk of further cardiovascular events, including aspirin, medications to lower blood pressure and cholesterol, dietary modification and exercise. Hackam et al. (2007) model the combined effect of these interventions and estimate that at least four fifths of these recurrent events could be prevented (or, at the very least, delayed) over five years, assuming additive effects and patient compliance. Even greater risk reductions were additional therapy to be included such as smoking cessation, glycaemic control and anticoagulation in appropriate patients.

Likewise, around 10% of individuals with a hip fracture will go on to have another fracture, usually within a few years of the first, equivalent to a risk some ten times higher than the general population, (Eliot-Gibson et al., 2004; George and Patel, 2000). A number of studies have demonstrated the efficacy of agents such as bisphosphonates, raloxifine, strontium or teriparatide in reducing the risk of a second fracture (NICE, 2011) and there is increasing consensus that they should be offered to patients who have suffered a hip fracture and in whom bone fragility has been documented upon further investigation. Similarly, interventions to prevent falls such as medication review, home modification, balance work and exercise and other risk reduction measures have also been shown to be both effective and cost-effective (Frick et al., 2010; Haines et al., 2004).

Hence identifying and treating underlying diagnoses such as elevated blood pressure or lipids, smoking, overweight and diabetic or pre-diabetic states in patients after a stroke, and osteoporosis or a tendency to falling in patients after a hip fracture is an essential element of high quality care. Identification and management is likely to be shared across primary and secondary care, however many national health systems, including Sweden's, increasingly expect primary care services to take on full responsibility for the long-term management of these conditions. The extent to which the primary care system in Sweden is currently equipped to meet these challenges is assessed in Chapter 2.

4.4. Quality initiatives and related outcomes in Sweden

Stroke care benefits from particularly ambitious national quality initiatives

In 2005, Socialstyrelsen published national guidelines on care for patients after a stroke (these were updated in 2009 and another update is planned for 2015). Part of a small set of about ten disease-focussed national guidelines, they are intended to support local and regional authorities in the prioritisation, resource allocation and organisation of stroke care and to support doctors and patients in making individual treatment decisions, according to the best available evidence adapted to the Swedish context.

The greater part of these guidelines focus on management of the acute phase of care, although one section is dedicated to post-acute care and rehabilitation. Of note, this section seeks to ensure individually tailored rehabilitation, stating that it is reasonable to discharge patients with mild to moderate symptoms from hospital earlier than normal provided that specialist multidisciplinary rehabilitation is available in the home, whilst patients with more severe strokes or with complex pre-stroke co-morbidities should not be offered early discharge.

Sweden also has an extensive set of Quality Registers monitoring the patterns and outcomes of care as described in Chapter 1. *Riks-Stroke*, the Quality Register for Stroke Care, was the first stroke register in the world to be established on a national basis, in 1994. It covers all Swedish hospitals admitting patients with a stroke and seeks to provide a comprehensive picture of the patterns of care and of quality; over 90% of first-ever strokes currently enter the Register (Asplund et al., 2011). The Register includes a wide range of patient reported measures, alongside clinical and process indicators, tracking patient outcomes for up to a year after their stroke and achieving an 80% follow-up rate. Examples of indicators include the proportion of patients admitted to a specialist stroke unit as opposed to a general medical ward or the proportion of patients reporting that their rehabilitation and home care needs were fully met, at three months and one year after their stroke. Detailed feedback is reported to each participating hospital and peer comparisons, disaggregated down to county and to hospital level, are published for public scrutiny (see Figure 4.5 for example).

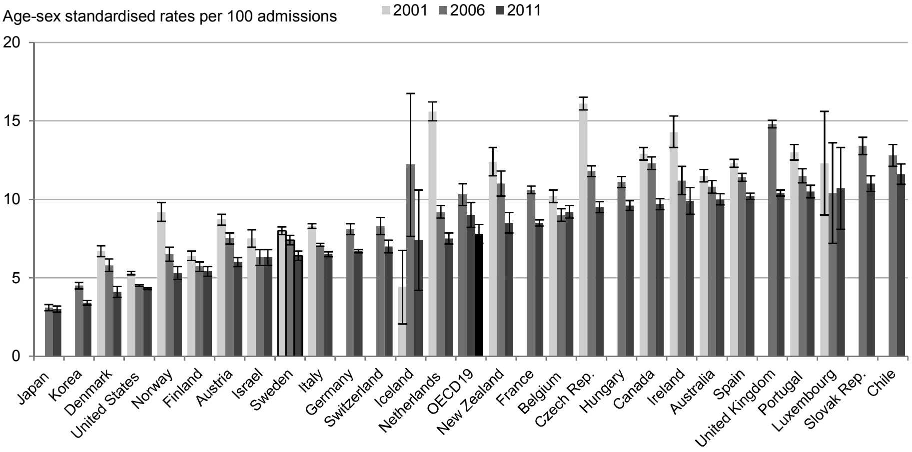
From its inception, *Riks-Stroke* was designed to be used as a quality improvement tool, with significant effort made to translate registry data into information which can be used, by planners, physicians and patients to seek improvements in stroke care. A recent advance along these lines was Socialstyrelsen’s publication of the first national assessment of the quality and efficiency of stroke care in 2011, with a particular focus on the co-ordination of care between municipalities and county councils (Socialstyrelsen, 2011). The report brings together multiple data sources on efficiency and quality, combining data from *Riks-Stroke*, social care registers, prescribing databases and additional specialised surveys to providers, in an attempt a comprehensive assessment of the quality of stroke care.

Such extensive quality architecture, comprising national guidelines, a long-established and far-reaching national quality register and national strategic performance reviews, has few parallels elsewhere −Sweden is one of very few countries to have developed a such comprehensive quality improvement process (comprising all elements of the Plan Do Study Act cycle) at national level. Other countries with comparable quality architecture in place are the United Kingdom, Canada and Australia; aspects of their comparative performance is set out below.

Outcomes for acute stroke services are better than OECD averages, but fall slightly short of Nordic comparators

The most recent in-hospital 30 day fatality rates from stroke in Sweden are significantly better than many other OECD countries but, as Figure 4.3 shows, reductions in fatality have been modest compared to most other countries and Nordic comparators significantly out-perform Sweden.

Figure 4.3. Reduction in admission based (same hospital) case-fatality within 30 days after admission for ischemic stroke, 2001-11 or nearest year

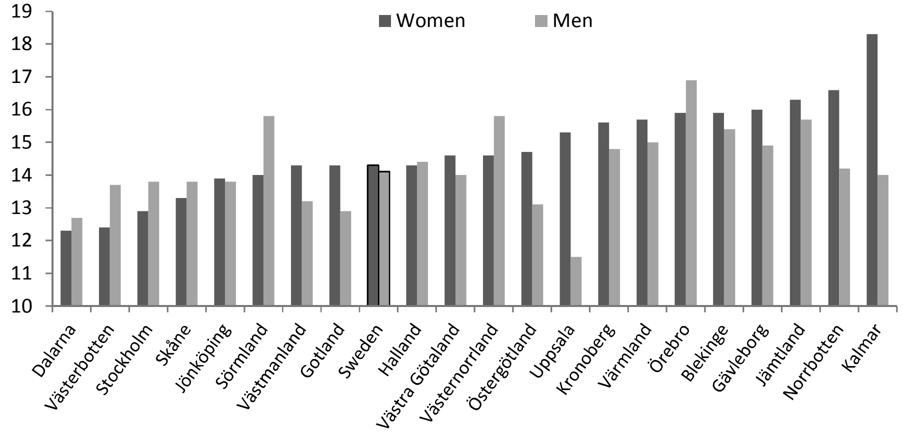


Note: Rates age-sex standardised to 2005 OECD population (45+). 95% confidence intervals represented by H.

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Sweden's relatively modest gains in the national survival rate over recent years will to some extent be related to the wide regional variation in fatality rates, differing by just over 50% in the case of women (Figure 4.4). Such differences may be due to differences in quality of care, differences in case-mix severity not captured by age standardisation or differences in the geographic accessibility of emergency care. Nevertheless, over 95% of patients, however, report being satisfied or highly satisfied with their quality of care during the acute hospital phase, with very modest regional variation (range from 93.9% to 98.5%).

Figure 4.4. 28-day case fatality rates for first ever stroke, hospitalised patients, age-standardised



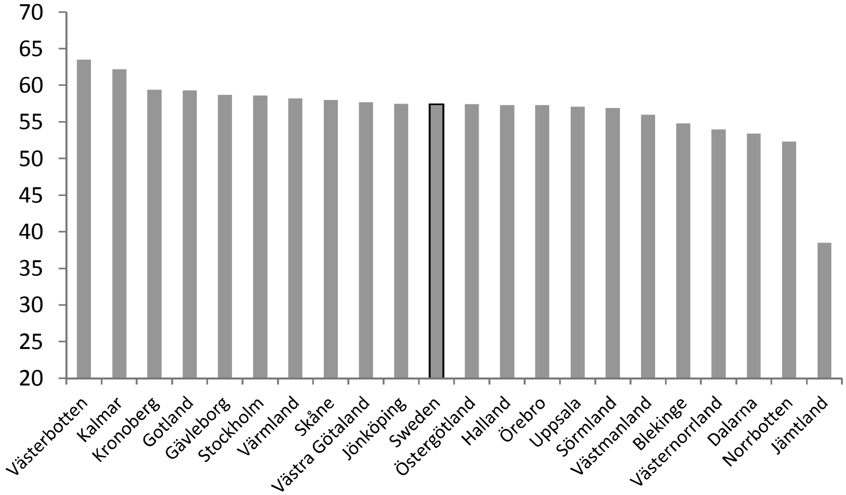
Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

The few indicators of post-acute care that exist suggest that quality of care falls after discharge

Although data relevant to on-going care after discharge from hospital (the focus of this chapter) is sparse, one indication comes from a corollary of the patient satisfaction rates reported above, namely the proportion of patients reporting that their rehabilitation needs had been met 12 months after the acute phase. Rates are low: only 57.4% nationally in 2010, with almost a two-fold difference across county councils as shown in Figure 4.5. The dispersion is more modest if Jämtland county, a clear outlier, is excluded, nevertheless in all counties, more than a third of patients report dissatisfaction with their rehabilitation programme.

Part of the explanation for these low satisfaction rates, and the significant regional variation, may be due to differences in how responsibilities are shared between county councils and municipalities. Part may also be due to unrealistic expectations of what rehabilitation should or could achieve, these figures should nevertheless prompt consideration of the reasons for an apparent dichotomy between the quality of acute hospital care and the quality of care after discharge. Much of this is likely to come down to the challenge of providing an array of community based services. There are reports that some patients and carers find rehabilitative care uncoordinated and fragmented and the recent proliferation of providers resulting from the choice and competition reforms confusing, an issue that was explored in detail in Chapter 2 on primary care. Likewise, the relative absence of guidelines, standards and monitoring frameworks for community based care compared to hospital care is likely to be an important explanatory factor, as explored more fully in Chapters 1 and 3.

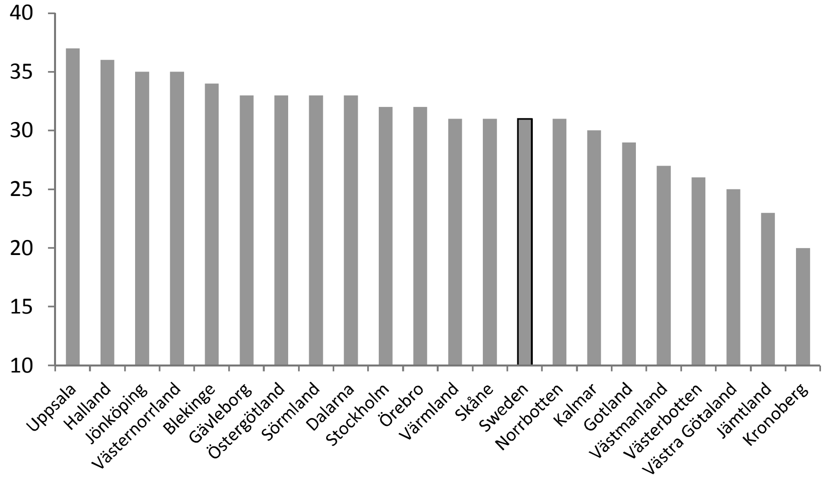
Figure 4.5. Percentage of patients reporting that their rehabilitation needs had been met 12 months after the acute phase, 2010



Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

A related – possibly more objective – indicator of the quality of rehabilitation concerns the proportion of patients returning to paid work after a stroke. In Sweden, this is around 31% (all ages), with an almost two-fold variation across county councils, as shown in Figure 4.6. Reassuringly, however, Sweden's average rate of return to work is broadly similar to that seen elsewhere. A study of 2 874 patients between 1995-2004 from a well-known research-focussed stroke register based in London, for example, reported that 35% of survivors had returned to work at one year (Busch et al., 2009).

Figure 4.6. Proportion of patients returning to paid work after a stroke one year after the acute phase, 2011



Source: Riks-Stroke (2011), *Årsrapport 2011*, The Swedish Stroke Register, available at www.riks-stroke.org/content/analyser/RS_arsrapport_2011.pdf (accessed on 14 Oct. 2013).

The quality architecture surrounding care after hip fracture is less developed

In contrast to care for patients after a stroke, there are no Socialstyrelsen guidelines to support care for hip fracture. Whilst osteoporosis is considered in the national guideline for musculoskeletal diseases, this focuses on the assessment and management of fracture risk, and care after hip fracture is not considered. Neither has there been a comprehensive national assessment and strategic review of the efficiency and quality of care after hip fracture, comparable to Socialstyrelsen's 2011 publication on stroke.

Lack of national guidelines does not indicate a lack, however, of local initiatives. Indeed, in terms of care pathways specified at service-level, Sweden appears to be a world leader. In a systematic review evaluating their impact internationally, Leigheb et al. (2012) identified 15 studies, five of which were from Sweden (others were from Canada, the United Kingdom, the United States and China). Furthermore, the Swedish evaluations were unique in looking at process measures to do with post-hospital care (it was found that using a care pathway brought about discharge planning meetings and contact with a social worker significantly sooner, Olsson et al., 2007).

Nevertheless, a linked study notes that, even in Sweden, care pathways remain relatively unknown (Olsson et al., 2009).

An important point of similarity between the two clinical areas is, however, the existence of a long-established and pioneering Quality Register. *Rikshöft,* or the Swedish National Hip Fracture Register, dates back to 1988 and was intended to complement pre-existing registers on hip and knee replacement procedures. *Rikshöft* went beyond these procedure-focussed registers, however, and collected information about the patient including level of functioning and social circumstances. The register's annual report publishes clinical observations such as fracture type, method of operation as well as outcomes such as walking ability and living accommodation at four months, disaggregated by age band, gender, region and hospital.

From its inception, *Rikshöft* has had an academic focus. Over 160 peer reviewed studies published using data contained within the register since the 1990s; these largely focus on pre-hospital and hospital aspects of care such as comparison of outcomes associated with different surgical techniques or acute service designs. Hommel et al. (2008), for example, study the impact of a new clinical pathway for hip fracture introduced at the University Hospital in Lund and find that surgery performed within 24 hours was significantly associated with reduced length of stay ($p<0.001$) and that mortality was significantly higher among medically fit patients in whom surgery was delayed for non-clinical reasons compared with patients with no delay ($p<0.001$). One example of a direct impact on clinical practice is *Rikshöft*'s identification of poorly performing brands of hip prosthesis. This translated into new clinical policy that eliminated their use, with estimated resultant savings of SEK 1 billion (EUR 100 million, USD 130 million) over seven years (Kurtz et al., 2007). Although published studies include examination of the effects of multidisciplinary care (e.g. Hommel et al., 2003) and the effects of hospital care over the longer term (e.g. Samuelsson et al., 2008), no studies directly examine the quality or effect of post-hospital care, the focus of this chapter.

The mere existence of a national hip fracture registry, especially one so well established, distinguishes Sweden vis-à-vis its peers−few other OECD countries have one. Norway established a hip fracture register in 2005; in the United Kingdom, the National Hip Fracture Database was launched in 2007 (building on a Scottish national audit dating back to 1999). Canada has published national guidelines but lacks a national audit of care, although regional initiatives are underway. Similarly, Australia and New Zealand are moving toward a shared registry, beginning with voluntarily participating centres.

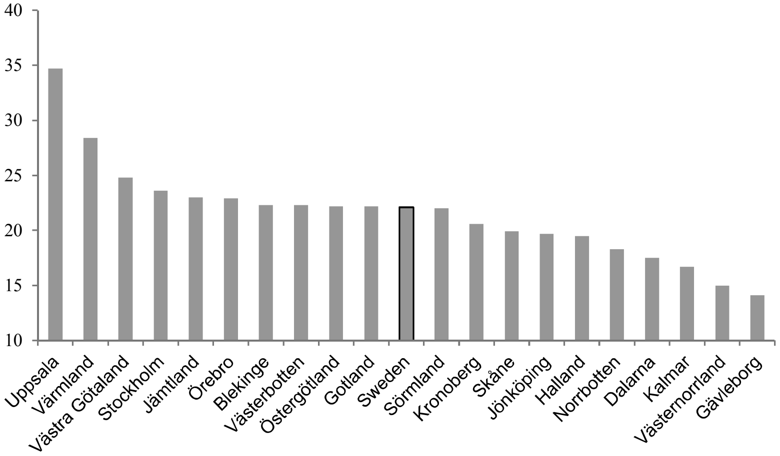
The European Union used *Rikshöft* as a template to develop the Standardised Audit of Hip Fractures in Europe (SAHFE) project in 1996, aiming to promote Europe-wide benchmarking of care and to disseminate best practice. SAHFE data is drawn from voluntarily participating hospitals and is not derived from national audits. Various studies comparing outcomes in different countries have been published although all, again, focus on the acute phase of care. Valaviciene et al. (2012), for example, comparing Sweden and Lithuania, report that Swedish patients reported significantly better self-care, felt less pain and discomfort, and had fewer symptoms of anxiety and depression at four month follow-up.

Acute care after hip fracture in Sweden is efficient and of high quality

Data from *Rikshöft* demonstrates that surgery on hip fractures almost always performed within 24 hours of admission. Mobilisation is also quick, usually the next day, and pain is well controlled. It is reported that discharges are rarely delayed for administrative reasons (such as lack of capacity in, or co-ordination with, the community sector), although this information is not routinely published. In terms of the timeliness of surgery, Sweden is in a small set of countries performing particularly well compared to other OECD countries, achieving rates of surgery performed within 48 hours of over 90% (along with Denmark, the Netherlands and Iceland according to the latest *OECD Health Statistics*). There has also been a steady increase in the number of hip fractures managed with full or partial hip replacement (which is more resource intensive but leads to better results than pinning) in certain patient groups.

Although *Rikshöft* data show no difference in waiting time to operation by age or by gender, a more than two-fold difference is apparent across regions, as Figure 4.7 shows:

Figure 4.7. Waiting time in hours for operation after arrival at hospital by region, women



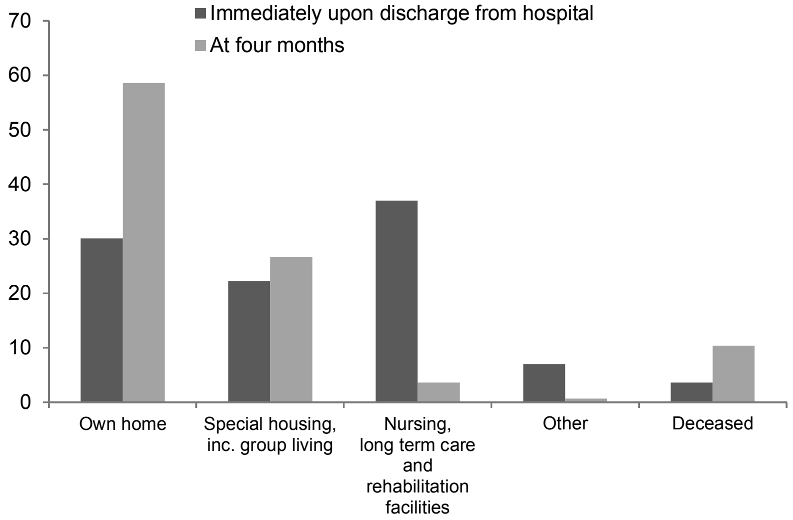
Source: Rikshöft (2011), *Årsrapport 2011*. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

As for stroke, little is known about post-acute care for hip fracture patients

Rikshöft publishes little data on the patterns or quality of care after the acute hospital phase. One indicator relates to patients' place of dwelling upon discharge from hospital. For patients living independently before a hip fracture, returning to their own home will presumably be a priority for most. The likelihood of returning home depends on patients' age and functional ability prior to the fracture, but also on the availability and effectiveness of rehabilitation – both early on in the acute hospital setting as well as in the community after discharge.

As Figure 4.8 shows, immediately after the acute hospital phase, the majority of hip fracture patients are discharged to a rehabilitation unit (35%), to their own home (30%) or to institutional care (18%). At four months, 59% are living in their own home and 23% in institutional care. These figures appear in line with the few international comparators that are available, although caution around direct comparison is necessary given the need to adjust for age and prior functional status. Data from the Scottish hip fracture register, for example, shows that 94% of 50-64 year-olds and 77% of 75-89 year-olds (living in their own home before fracture) were living in their own home four months after their fracture, with 1% and 8% respectively in institutional care and 2% and 10% on a rehabilitation ward (Holt et al., 2008).

Figure 4.8. Place of dwelling after hip fracture



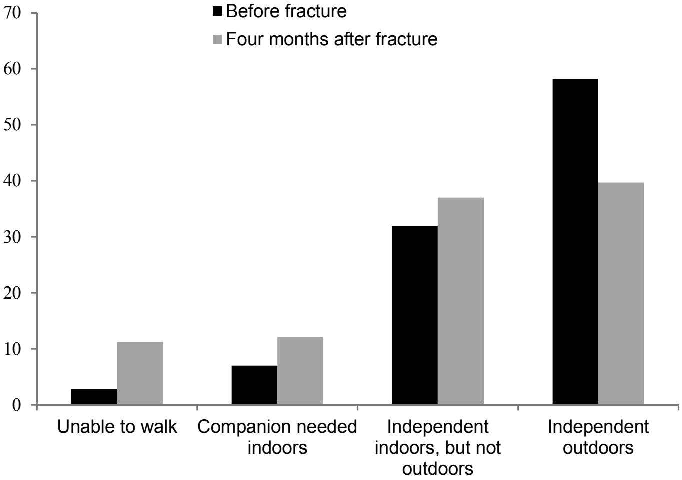
Source: Rikshöft (2011), *Årsrapport 2011*. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

A related indicator concerns patients' mobility. There has been a small increase in the proportion of people walking fully independently (that is outdoors without assistance) over the lifetime of the register and is currently around 40%, for all ages, as shown in Figure 4.9. This figure is in line with international comparators. Data from the Scottish hip fracture register, for example, shows that 41% of 50-64 year-olds and 22% of 75-89 year-olds able to walk unaided and unaccompanied before fracture were able to walk unaided and unaccompanied four months after their fracture (Holt et al., 2008).

Of note, *Rikshöft* does not contain any patient reported outcome measures in the way that *Riks-Stroke* does. It does not, for example, ask whether patients feel satisfied that their rehabilitation needs have been met. This is in contrast to registers elsewhere. In the United Kingdom, for example, national audit data indicates that 74% of patients after hip fracture report feeling fully satisfied that their rehabilitation needs have been met at three months (Royal College of

Physicians, 2010), although this varies between 42-98% across hospitals. Studies with internationally comparable data on the quality of rehabilitative care are lacking.

Figure 4.9. Walking ability before and after hip fracture



Source: Rikshöft (2011), *Årsrapport 2011*. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

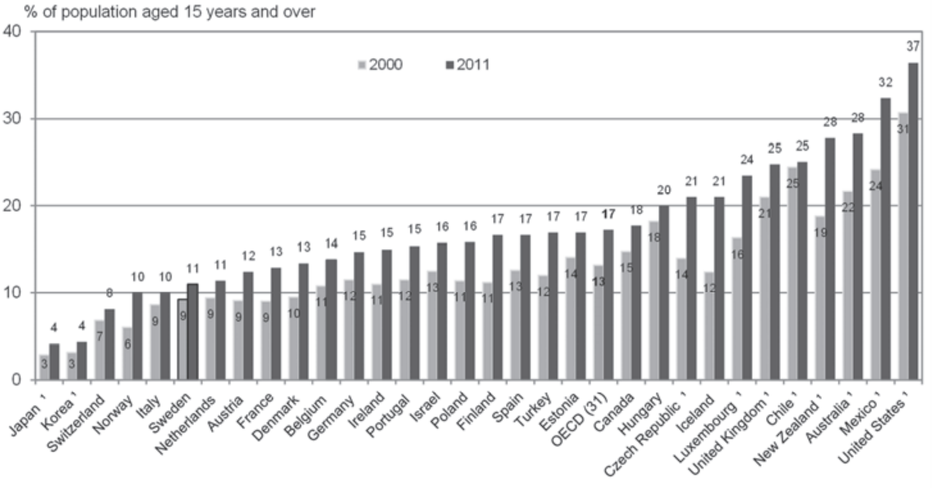
4.5. The pathway of care after stroke or hip fracture in Sweden

Significant primary prevention efforts are made to reduce the incidence of first stroke or hip fracture

As noted earlier in the opening paragraphs of the chapter, the incidence of stroke in Sweden – as indicated by hospital discharge rates – is falling, thought to be due to better management of primary risk factors. Figure 4.10 demonstrates how Sweden has a relatively low adult obesity rate, one of the major cardiovascular risk factors, amongst OECD countries and with only a modest increase in prevalence over the past decade. Smoking prevalence, at 14%, is the lowest amongst OECD countries. Although consumption of smokeless tobacco (snus) is common in Sweden, this has a much less adverse cardiovascular risk profile than smoking (Hansson et al., 2009).

Primary preventive efforts are especially important for hip fracture, given Sweden's northern latitude. The country has a long history of implanting falls prevention programmes and is a leader of the international research agenda in this field. Multidisciplinary community based interventions have been shown to be particularly effective. A local campaign involving elderly residents, pharmacists, opticians, shoe retailers, and fitness centres in Södertälje, for example, was associated with a 17% reduction in falls in men and women aged over 55 (Larsson et al., 2010).

Figure 4.10. Prevalence of obesity among adults in OECD countries, 2000 and 2011 or nearest year



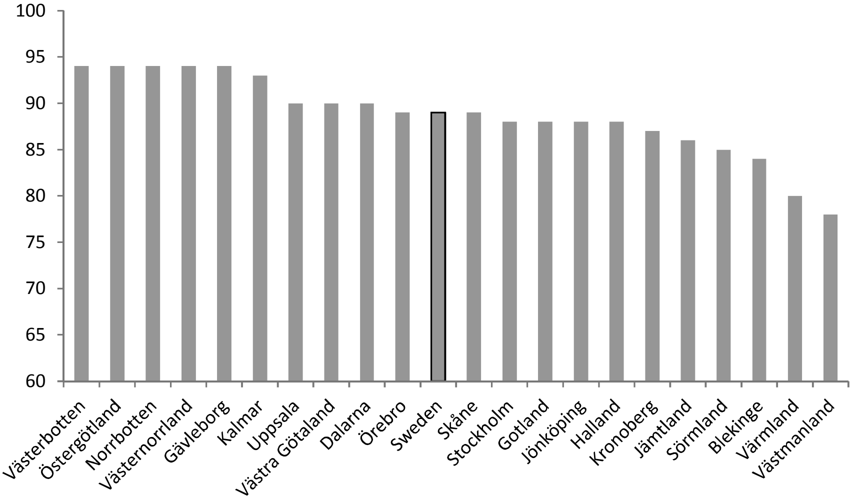
1. Data are based on measurements rather than self-reported height and weight.

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Most stroke and hip fracture patients are cared for in specialist units and enter a dedicated care pathway

In 2011, 89.1% of patients with stroke were admitted to a stroke unit at some point in the acute phase (see Figure 4.11). Around three quarters of patients were directly admitted to a stroke unit or intensive care unit after arriving at the hospital. Furthermore, in a specially conducted survey in 2010, it was reported that 15 of 76 hospitals had routines for immediately transporting stroke patients from the ambulance to the radiology department for a CT-scan (Socialstyrelsen, 2011).

Figure 4.11. Percentage of stroke patients admitted to a designated stroke unit during any part of hospital stay, 2011



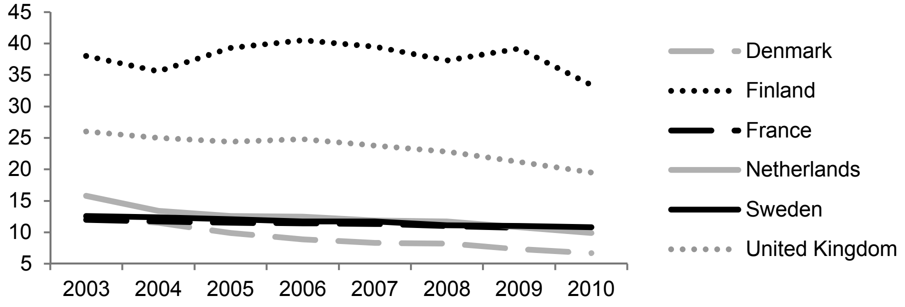
Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

Parallel data for hip fracture patients, relating to the proportion of this group admitted on a specialist care pathway, is not available.

Patients are leaving hospital earlier and more is being asked of municipality-led health care

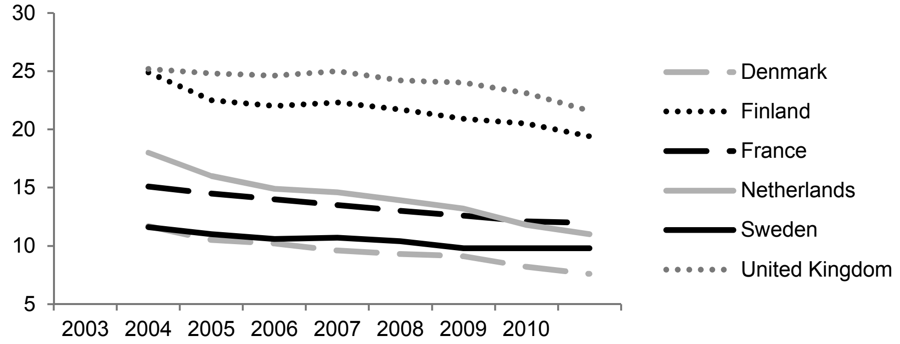
As discussed in preceding chapters, there is an increasingly acute element to the care that municipalities are being asked to provide. Figures 4.12 and 4.13 show how length of hospital stay has decreased over recent years for both stroke and hip fracture, from an already low baseline compared to other countries. Although part of this reduction may be explained by quicker and more effective treatment, a significant driver is the expectation, on the part of both patients and administrators, that more care be delivered outside the hospital. Indeed, Sweden was a pioneer of the early supported discharge model described in Section 4.3. In the case of hip fracture, patients' discharge destinations were discussed in detail in Section 4.4 – the majority are discharged to a rehabilitation unit (35%), to their own home (30%) or to institutional care (18%). All of these sites fall under municipality responsibility.

Figure 4.12. Trends in length of stay after stroke



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Figure 4.13. Trends in length of stay after hip fracture



Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Once discharged, patients who have suffered a stroke or hip fracture are likely to need a complex array of on-going services to restore their independence and functioning as far as possible. These will include some or all of the following: physiotherapy, to help with strength, balance and mobility; occupational therapy, to help with safe management of the tasks of daily living such as washing, dressing and preparing meals; speech and language therapy, to help with communication and, in some cases, swallowing; clinical psychology, to help with any psychological sequelae such as anxiety or depression; social services, to help with access to appropriate benefits, accommodation and employment; and medical and nursing care to provide clinical care. The needs of each individual will be unique and will not be constant over time, hence it is essential, both from a patient-centered and system-centered point of view, that services are provided in an co-ordinated and responsive manner, to ensure that needs are met and that services are not duplicated, delayed or take contrary approaches.

It is not always clear, however, for both hip fracture and stroke patients, that municipalities are adequately equipped to manage patients coming out of hospital earlier and earlier. Although generally well resourced, there are reports of deficiencies in both the skill-mix of municipality staff, and the care processes they use, in relation to meeting patients' needs upon discharge from hospital. Regarding skill-mix, there are fewer stroke specialist nurses in the community compared to other long-term conditions, such as diabetes. Specialist nurses have a particularly critical role to play in co-ordinating patients' care after discharge, identifying and managing early signs of deterioration and avoiding readmission, and providing reassurance to patients and their families. Currently, the professionals with whom discharged patients are likely to have the most extensive contact are home care staff. These carers have basic nursing education, but lack specific training in rehabilitation.

There is a requirement that municipalities identify the frail elderly and other residents in need of rehabilitation and develop an individualised care plan for each of them. Defining who these patients are and the level of detail in each plan is reported to be inconsistent, however, across municipalities. Similarly, prior to leaving hospital, multidisciplinary discharge planning meetings involving municipality services are mandated to happen for every patient requiring on-going care in the community. Again, there is inconsistency in identifying these individuals, in the multidisciplinary professionals attending the meeting and in the depth and detail of discharge planning that occurs. As noted earlier, this may be due to regional variation in how responsibilities for post-discharge care are shared between county councils and municipalities.

Secondary prevention is of low quality in Sweden

As noted earlier, secondary prevention must be seen as a central element of care and rehabilitation after a stroke or hip fracture. In the case of stroke, the steady downward trend in the rate of hospital readmission after a stroke (from around 11% readmitted within a year in 1994 to around 9% in 2008) suggests that the quality of secondary prevention is improving in Sweden. There is evidence, however, which indicates that specific aspects of secondary prevention are poor, particularly once the patient leaves the hospital setting.

Upon discharge, *Riks-Stroke* reports that 92.0% of patients with an ischaemic stroke are on an antiplatelet or antithrombotic agent such as aspirin or warfarin (Riks-Stroke, 2012). This rate is amongst the best in the world and compares well with rates reported in other countries, such as 89% in the United Kingdom's national audit (RCP, 2011) or 91% in Canada's (CSN, 2011). Other indicators of secondary prevention, such as the proportion of patients leaving hospital on antihypertensive or lipid lowering medication also compare well against international peers.

On-going care after the hospital episode, however, appears to present a problem. Data from *Riks-Stroke* demonstrates that three months from discharge from hospital, around one in six patients have had no contact with a physician or specialist nurse, with substantial variation across counties. Even for those in whom secondary preventive treatment is started, Glader et al. (2010) have shown that use evidence-based secondary preventive medications such as aspirin, statins to reduce blood cholesterol and blood pressure lowering medications falls to 60% of Swedish patients or fewer, two years after a stroke. This is despite the fact that national guidelines call for regular review, at least yearly, of risk factor management.

Although *Riks-Stroke* does not collect information on clinical outcomes related to secondary prevention, an indication of their likely impact comes from Sweden's quality register for heart disease. This register finds that only around one in six patients (range 0-40%) managed by hospital outpatient clinics after a heart attack simultaneously achieve the four goals of systolic blood pressure being less that 140mmHg, total cholesterol being less than 2.5 mmol/L, stopping smoking and enrolling in a physical training programme (the figure amongst patients managed by primary care physicians is unknown) (range 0-40%). There is no reason to assume that risk factor management amongst stroke patients would be any better.

Secondary prevention after a hip fracture is also inadequate. In Sweden, less than one in six patients nationwide are on preventive treatment six to twelve months after a fracture (with treatment rates across counties varying from 7% to 22%), far short of the 60-70% rate that most scientific studies conclude is necessary, taking into account those with and without osteoporosis (Socialsytrelesen, 2012).

Secondary prevention of hip fracture is known to be poor in other countries. A relatively recent systematic review of 37 studies (Elliot-

Gibson et al., 2004) reported a median rate of osteoporosis investigation in patients who had sustained a fragility fracture was 11% (0.5-32%), with only very small numbers of patients, around 10%, going on to receive treatment with calcium, vitamin D or bisphosphonates to prevent further weakening of their bones. Estimations by Ström et al. (2011), however, place Sweden in a more unfavourable light: Sweden's osteoporosis "treatment gap" for women, that is the difference between the number of women that epidemiological data suggest need treatment and the number of women that sales data suggests are receiving treatment, is 71% for women, compared to 19% in Spain, 41% in France, 56% in the United Kingdom, 60% in Italy and 75% for Germany. Of note, the "treatment gap" counts women in need of either primary or secondary prevention.

4.6. Achieving better quality care after stroke and hip fracture

Developing joint health and social care guidelines or standards should be considered

As described in earlier chapters, Sweden recently set out its broad national vision on health and social care for the elderly. Detail is lacking, however, for discrete clinical areas. The absence of clinical guidelines for hip fracture care is an obvious deficiency, which should be addressed with some urgency given the substantial individual and public health burden that hip fractures cause, and the complexity of health and social care demanded after the acute event. Even where guidelines exist, as in the case of stroke, there is a case for revisiting them to ensure that they fully encompass the breadth of care and services that a patient will make use of.

Currently, joint health and social care guidelines only exist for dementia, alcohol or substance abuse and schizophrenia. The case for jointly developed health and social care guidelines in the case of stroke or hip fracture is no less strong. Sweden should also consider going beyond guidelines to set out minimum quality standards that encompass both health and social care. Although defining standards may signal a departure from Sweden's traditional supportive rather than directive governance model, it fits with broader trends within the health and social care landscape and is a necessary response to public demands for the consistent and transparent assurance of the quality of care.

In some cases, the needed guidelines or standards can be easily identified: guidance around discharge planning, for example, should specify more clearly who should be present, the level of detail in the discharge plan and the timeframe, given the inconsistency in discharge planning referred to earlier. In other cases, the novelty and rapid innovation in how health and social care services are provided means that evidence of what works best may be not be plentiful. Here, it may be an option for guidelines to showcase what appears to have worked well in some settings rather than be prescriptive. Given the strong local character of governance and administrative arrangements in Sweden, national guidelines should always allow for local innovation. Equally importantly, guidelines should emphasise responsiveness to user feedback as a particular priority, given the historical tendency for municipalities to be relatively slowly responsive to this type of information, as described in Chapter 1.

Better frameworks for monitoring the quality of on-going care outside the hospital setting are needed

Having achieved a clearer definition of what constitutes good quality community care after stroke or hip fracture, emphasising closer working between health and social care services, a framework can be developed to monitor implementation. The difficulties here should not be underestimated – quality assessment of community care is a nascent area and no country has yet developed a comprehensive monitoring framework for health care delivered outside traditional settings (that is, hospitals and primary health care). Patient reported measures are likely to be key, and should be as fully developed as possible, whilst acknowledging the difficulties of asking patients and carers questions that are simultaneously comprehensible to them and actionable to service providers.

Sweden’s pioneering quality registers form the starting point for strengthening the monitoring framework. Some routes for strengthening could be identified from monitoring frameworks in other countries: England’s Care Quality Commission, for example, disaggregates rehabilitation into several areas (such as occupational therapy, speech therapy, assistance with returning to work). Although costs (including the time and good will of the respondent) are implied with each additional question or level of detail added to a quality register, it is essential to ensure that they are as relevant and informative as possible.

Frameworks for monitoring quality need to keep abreast of changes in how services are provided; in Sweden’s case it is particularly important, for example, that quality monitoring is sensitive to the service changes brought about by the choice and competition reforms. Dedicated patient surveys may be the best means to monitor the impact of changes in service configuration, rather than quality registers. Nevertheless, quality registers can usefully include high-level measures of whether services meet patients' needs. *Riks-Stroke* includes a patient-reported measure on whether rehabilitation needs have been fulfilled at three months and one year. This data is not collected as part of *Rikshöft* yet is highly relevant information, particularly in the context of recent organisational shifts in the provision and responsibilities of care.

The quality architecture around stroke and hip fracture, and other similar conditions, should be made more equal

Despite stroke and hip fracture being broadly comparable in terms of incidence rates, the depth and breadth of care needs that they trigger, the relatively advanced evidence bases setting out optimal care and the marked regional variation within Sweden regarding process and outcome measures, the quality architecture around the two conditions is rather unequal. As described earlier, stroke care, for example, benefits from national clinical guidelines and a national performance report from the National Board of Health and Welfare, bringing together diverse data sources and making strategic recommendations for future service development. There are no equivalent guidelines or national performance report for care after hip fracture. The contents of the two quality registers also differ, that for stroke including patient satisfaction measures as noted above, which are not included in the hip fracture quality register.

Reasons for these differences lie in the distinct historical trajectories that quality improvement initiatives for each area, largely led by clinical professionals working in the field, have taken. While this bottom-up approach has some advantages, including freedom to innovate and develop initiatives that best meet specific needs, it is also an illustration of the inconsistent approach taken to quality assessment, assurance and improvement in Sweden. This could now benefit from greater standardisation at a national level. The need to take a standard approach to quality in clinical domains such as stroke and hip fracture is particularly important because the pathway of care for these conditions crosses several boundaries (that between primary and secondary health care and between health and social care in particular) and is central to Sweden's ambition to achieve better integrated care.

Formulating a more consistent quality approach to distinct clinical areas will require the Swedish authorities, in association with professional and patient groups, to set out the quality architecture it wishes to see in place for each area. This may include minimum quality standards, joint health and social care guidelines, quality registers that include patient experiences, regular national strategic reviews and so on. Special attention should be paid to assuring quality for the frailest elderly and ensuring that any risk of fragmented care engendered by choice and competition reforms are minimised. Frameworks set out at national level should not restrict local freedom to establish additional quality architecture and must fully embrace the reality of multiple alternative providers and an expanding market place of health and social care solutions.

Local innovation should continue to be supported and good practices disseminated

Nationally determined guidelines, quality standards and monitoring frameworks need not stifle local innovation to develop solutions that best meet local needs. There are several examples of innovative working by municipalities that might benefit from wider roll-out. Many of these involve pro-active risk stratification of discharged patients and instigation of appropriate preventive care. A local initiative that telephoned discharged patients a day, and a week, after discharge reduced readmission rates by 30-40%, for example, and another in which a geriatrician and two nurses looked at the case notes of all readmitted patients, identifying and managing what they felt to be avoidable root causes of readmission, was reported to have led to significant reductions in admissions and lengths of stay in the following year.

Broader, systemic reforms may also play a role, particularly for less complex patients needing less tailored care. In Stockholm County a bundled payment initiative, for example, offered providers of elective hip and knee replacements a fixed price that included a pre-paid premium for rehabilitation and post-operative complications, including readmission (a form of “bundled payment”). Perhaps expectedly, length of stay reduced, and throughput and productivity increased; more surprisingly, scheduled follow-up visits *increased*, as providers instituted more pro-active care to reduce risk of more costly complications. Patients were found to prefer this system and quality registers showed better care.

It is important that the impact of innovations such as these are robustly evaluated and learning shared with other municipalities. With regards to bundled payment initiatives, for example, there issues to resolve around the fact that the split between county councils and municipalities complicates whole-pathway reimbursement and results monitoring and that bundled payment models entail the risk that responsibility for a patient's care is not continuous, but contracted to end at a certain point. Choice and competition between multiple providers may also entail a risk of increasingly fragmented care, and this should form a particular focus of any evaluation.

At present it does not always appear to be the case that innovations shown to be successful in one area are trialled elsewhere. The Swedish authorities need to develop better mechanisms to enable contact and exchange between municipalities. This might best be organised on a county by county basis as a first step, with a central co-ordinating agency such as SALAR developing guidelines around which parties should be invited, which responsibilities need to be identified and how they might be shared out. It would seem particularly important to invite local universities to participate in these exchange fora, to support the evaluation of new projects. Inviting partners from local industry may also be valuable to advise on the diffusion of innovation.

Secondary prevention needs particular attention

Although Sweden has historically preferred to avoid use of centrally determined standards to direct locally provided services, one area where more directive guidance could be of use would be around secondary prevention. Clear responsibilities for ensuring effective secondary prevention need to be assigned. In theory, secondary prevention can be managed either through hospital out-patient clinics or through primary care, but given the trend to shift care outside the hospital setting as much as possible and the need to situate secondary preventive efforts in the context of a patient's complete medical record and medication history, it seems more sensible that the task should be taken up by primary care. The importance of an identified co-ordinator is brought out in work by The International Osteoporosis Foundation (a group of independent, not-for-profit national osteoporosis societies working with a committee of scientific advisors and corporate advisors) who, reviewing systems for secondary prevention of fracture internationally, found that two-thirds of such systems employed a dedicated co-ordinator who acts as the link between the orthopaedic team, the osteoporosis and falls services, the patient and the primary care physician (known as "Fracture Liaison Services" or "Osteoporosis Co-ordinator Programs" for example).

Having clarified responsibilities, more effective secondary prevention could be achieved by setting out standards or guidelines for secondary prevention after cardiovascular events and fragility fractures at any site. Guidelines should also be published in a format understandable to patients and patient-oriented decision aids (setting out risks and benefits visually, for example) should also be considered. Adequate monitoring of secondary prevention should be ensured, either by including additional data points within the relevant quality registers or ensuring appropriate data linkage with other sources such as prescribing databases. Targeted and time-limited financial incentives may be appropriate to support implementation. In the United Kingdom a financial incentive to stimulate assessment of bone health and assessment of the risk of falls is thought responsible for the fact that 86% of patients now receive both bone protection medication, such as calcium and vitamin D preparations, as well as an assessment of their risk of falling by the time of discharge, and a further 8% either one of these two (NHFD, 2012).

Thought should also be given to improving primary prevention. The reason for a patient's fall, for example, is not entered in the hip fracture register; hence it cannot be used to inform preventive work at a public health level. Of particular note, possible linkage between this Register and Senior Alert should be explored, since there is promising evidence of Senior Alert's impact on reducing use of medications associated with impaired orientation and increased risk of falling. More broadly, as mentioned in Chapter 1, there is huge potential to get a deeper understanding of the quality of *system* care for elderly patients with multiple long-term conditions by overcoming the legal and technical impediments to cross-linking patients' data in multiple registers.

Sweden has an international role to play in benchmarking and improving health and social care

At country level, little is known about the quality of post-acute care. This is not for lack of evidence on what should be offered or what might be measurable – in terms of rehabilitation, secondary prevention and psychological support – and seems paradoxical given that the widely observed trend for an ever shorter acute phase of care, matched with a commensurate increase in what is being asked of post-acute services based in the community. Instead, this lack of knowledge is probably due to community services' relative inexperience with the culture of efficiency measures, quality monitoring and public accountability.

Beyond national systems, frameworks for the international comparison of post-acute care are even less well developed. The few national indicators of post-acute care that exist do not map easily onto one another to facilitate benchmarking. This becomes evident in the clear gap in international comparative efforts such as the OECD Health Care Quality Indicator project: this contains a well-established set of indicators of acute hospital care, of primary care for chronic diseases and of long-term residential care, but no indicators which pertain to post-acute care based in the community, which can be so strongly determinant of patients' recovery and quality of life.

Sweden has an opportunity to contribute here, given its long established efforts and pioneering ambitions. Efforts are underway to establish an international minimum dataset to compare the quality of stroke care – in which Sweden is involved – and the same should be done for care after hip fracture. The benefits to Swedish health care would be immediate since it is currently very difficult to comprehensively benchmark the quality of Swedish care against that of other countries.

4.7. Conclusions

Sweden is well experienced in using many approaches to encourage high quality health care, including guidelines, monitoring frameworks and powerful use of incentives such as Open Comparison or targeted financial bonuses. Regarding stroke care, Sweden has extensive quality architecture in place at a national level, comprising all stages of the Plan Do Study Act cycle. Quality architecture is less extensive for care after a hip fracture (lacking, in particular, national guidelines and any comprehensive strategic performance review) but is nevertheless far ahead of most other countries given the existence of *Rikshöft* and the extensive use made of its data in improving the efficiency and quality of care. As a general point, however, nearly all elements of the quality architecture for both clinical areas concerns hospital care – guidelines and monitoring frameworks only superficially address post-acute care, if at all.

This is clearly regrettable given the importance of post-acute care in determining the functional recovery of stroke and hip fracture patients. Furthermore, given Sweden's recent reforms to shift increasing responsibility for this phase of care to municipal authorities, which previously had had only limited responsibilities in the health domain, the need to quality assure post-acute health and social care is particularly pressing. Little is known about the patterns or quality of on-going care after hospital discharge. This is the case not just in Sweden, but internationally, which precludes a convincing assessment of the comparative performance of this sector of Sweden's health care system. Addressing this deficit is self-evidently necessary. Rather than leaving the assessment there, however, a number of further recommendations can be made by identifying gaps or weaknesses in the quality architecture that exists. These include developing joint health and social care standards and guidelines, ensuring that quality monitoring frameworks reflect changes in how services are organised and provided, using community rehabilitation resources more imaginatively and effectively and devoting particular attention to secondary prevention and palliative care.

These recommendations should be extended to other clinical areas beyond stroke and hip fracture. Although these two conditions are paradigmatic causes of sudden and unexpected disability, requiring a complex and tailored array of health and social care services to restore the patient as fully as possible to her prior level of health, opportunities should be sought to apply the underlying principles of quality assurance and improvement to other clinical areas such as care after other fractures, heart attack, major surgery, external injury or during the care of debilitating illnesses which may have an unpredictable course, such as multiple sclerosis. In parallel, there is a need to avoid a myopic view which focusses exclusively on post-acute clinical care. Care should be seen as part of a continuous pathway, in which primary prevention is also fundamentally important, and which is holistic, addressing the importance of high quality housing over the longer term for example, rather than just immediate clinical and social care concerns.

Note

1. Number needed to treat (NNT) is a measure of the effectiveness of an intervention and refers to the number of patients that need to receive the intervention in order to prevent one adverse outcome.

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