

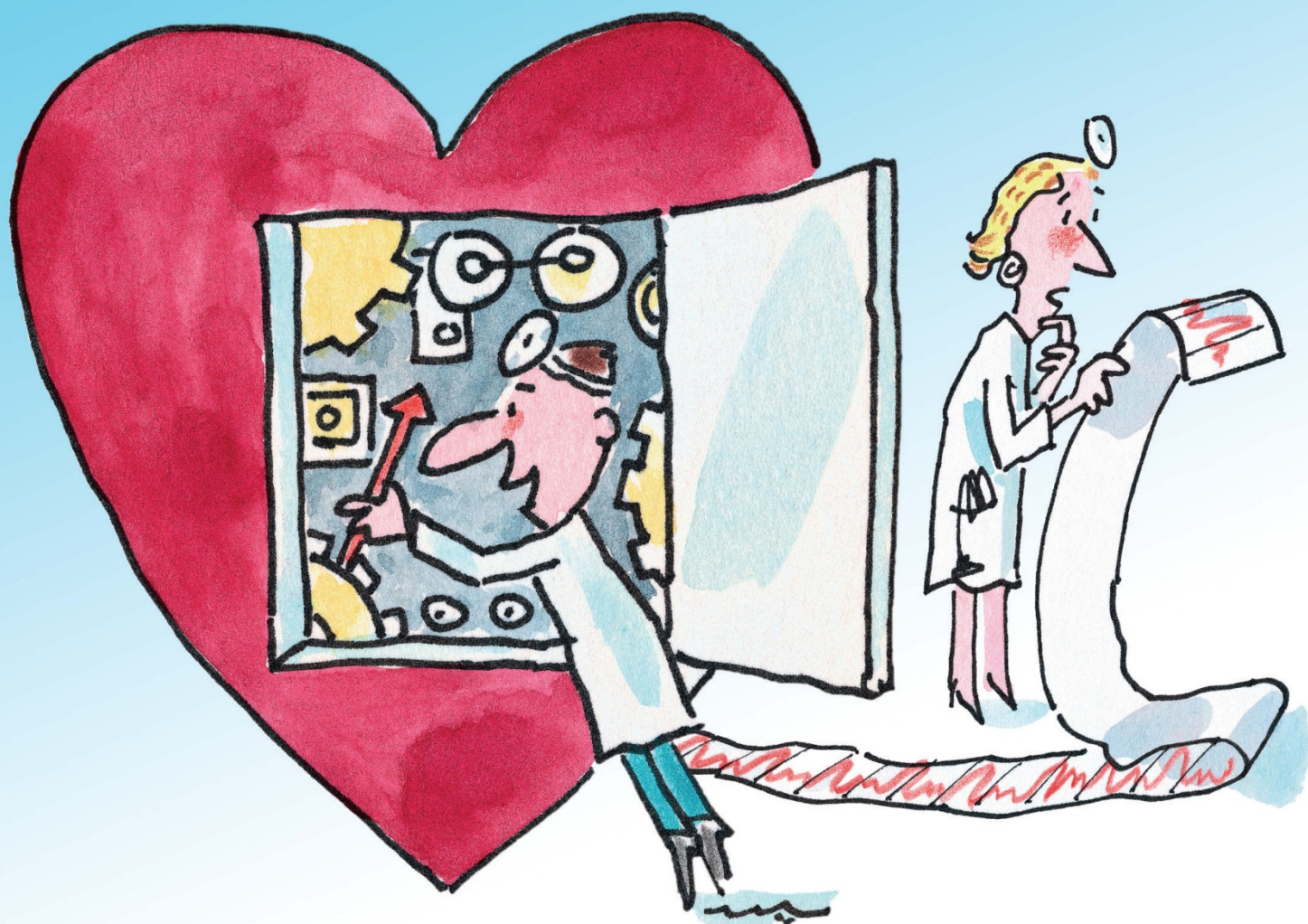


OECD Reviews of Health Care Quality

SWEDEN

EXECUTIVE SUMMARY,
ASSESSMENT AND RECOMMENDATIONS

12 December 2013



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 publicly 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 a 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.