IMPROVING CARE FOR PEOPLE WITH CHRONIC CONDITIONS IN WALES

What lessons are there from Denmark and Sweden?

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Background and Introduction

Health care systems throughout the world are rising to the challenge of chronic conditions. Wales is no exception, with the Profile of Long Term and Chronic Conditions in Wales showing that:

- there is a higher proportion of reported limiting long-term illness in Wales (23%) compared with England (18%), Scotland and Northern Ireland (20%)
- one third of adults report having at least one chronic condition
- two thirds of over 65 year olds report having at least one chronic condition, with two thirds having multiple chronic conditions
- three quarters of 85 year olds report having a limiting long term illness
- the most commonly reported chronic conditions treated in Wales are arthritis (14%), followed by respiratory conditions (13%) and chronic heart conditions (9%)
- considerable geographical variations in reported long term limiting illness have been identified, ranging from 19% in Cardiff to 30% in Merthyr
- intensive users of inpatient services have on average three chronic conditions
it is estimated that there will be a 12% increase in adults with at least one chronic condition and a 20% increase in those aged over 65 by 2014.

The 10 year strategy for health and social care in Wales, Designed for Life, set the target of achieving world class services in Wales. Recognising the ambitious nature of this target, the National Leadership and Innovation Agency for Health Care, in partnership with the Welsh Assembly Government and the Welsh Local Government Association, commissioned the Health Services Management Centre (HSMC) at the University of Birmingham to organise a study tour to two European countries.

The focus of the study tour was the management of chronic conditions. Specifically, HSMC was commissioned to arrange a study tour to two small countries in Europe with public services analogous to those in Wales and where there was potential for learning from the experience of these countries. In view of the involvement of senior leaders from local government as well as the NHS, one of the aims was to understand how health agencies worked together with local authorities in other parts of Europe in addressing the needs of people with chronic conditions.

On the basis of this brief, Denmark and Sweden were chosen for inclusion in the study tour. Both countries have made a long term commitment to high quality public services, and their social democratic philosophies are in line with those adopted in Wales post-devolution. Furthermore, in both countries local government plays a major part in the funding and provision of public services, including health and social care. Last but not least, Denmark and Sweden are broadly comparable in size and scale to Wales, thereby offering greater potential for learning than much bigger countries such as France and Italy.

Based on HSMC’s experience of organising international study tours, participation was based on three groups of three senior leaders drawn from NHS agencies and local authorities in different parts of Wales. The rationale for this was to enable each group to learn together during the visits that were made and to follow up these visits with a project that they would jointly take forward in each area. As well, participants included four senior leaders from national organisations in Wales, with the responsibility for distilling the learning from the study tour at the All Wales level.

The aim of this paper is to summarise the lessons that emerged from the study tour and to ensure that these lessons are disseminated as widely as possible among public service leaders throughout Wales.
Lessons from Sweden

The Swedish System

Sweden's population of 9 million has access to comprehensive health services which are provided under the terms of the Health and Medical Services Act of 1982. The Act aims to provide health care that is accessible to all citizens on equal terms. The overall goal is good public health and high quality health care at reasonable cost.

The health care system is decentralised, being funded and organised through 21 county councils and 290 municipal councils. National, regional and local elections are held on the same day every four years. National government sets the legislative and policy framework, and county councils (in effect, elected health authorities) are responsible for the provision of health services at the regional level.

Municipal councils are responsible for community health and social care services in their areas (and most other local government services). Many of the municipal councils serve populations that are small by UK standards. Municipal councils collaborate with each other to provide services/share expertise where appropriate.

Most of the funds for health care (80%) are raised through local income taxes. Both county councils and municipal councils levy taxes and these are supplemented by grants from national government. A tax equalisation scheme ensures that county councils and municipal councils have similar levels of funding to allocate to health services. Patients are required to contribute to the cost of some services e.g. GP visits and hospital stays, subject to an annual cap.

Sweden performs well when compared with other countries. Health outcomes, as measured by indicators such as life expectancy and infant mortality, are among the best in the world. Health care expenditure at around 9% of GDP is close to the OECD average and quality of care and access to services are generally considered to be good. Legislation dating from 1992 has eliminated the problem of delayed transfers by placing on municipal councils the responsibility for paying the cost of care in hospital of patients who are ready to be discharged.

However, Sweden also faces challenges in a number of areas including: a bias towards acute hospital services, at the expense of primary care (GPs do not act as gatekeepers and patients can go directly to hospital); problems for patients in accessing primary care for non-urgent conditions; and the need to reorient towards the prevention and treatment of people with chronic conditions, including bringing about closer coordination between county councils and municipal councils.

In addition, the health care system is faced with the prospect of changes following the election of a centre right government in last year's elections and
a recent report on the organisation of Swedish government. The new
government is expected to introduce reforms to address some of the above
challenges, for example, by encouraging more entrepreneurial models of
primary care provision. The report on the organisation of Swedish
government may also lead to a reduction in the number of county councils
from 21 to between 6 and 9.

The Study Tour

The two day study tour was hosted by the Health and Hospital Care
Department of Skane Region in southern Sweden. After an introduction and
overview of the Swedish system in general and the Skane region in particular,
participants heard presentations on stroke care services and work on
improving processes in health care through redesigning clinical pathways.
This was followed by site visits to health care facilities in Lund, Malmo and
Kristianstad.

These facilities included hospital and primary care services, with a particular
emphasis in a number of visits on initiatives to strengthen the co-ordination of
care for older people through closer integration of services provided by the
county council and municipal councils. Skane is currently placing increasing
emphasis on ‘nearby care’ and many of the initiatives that were presented
were examples of this.

The study tour concluded with a presentation by regional politicians on the
reconfiguration of hospital services in Skane and a round table discussion
with participants.

Key Lessons and Questions

The following themes emerged as being of particular interest to the NHS and
local government in Wales:

1. Health services are run on a much more decentralised basis than in
Wales. This means that the role of national government is quite different.
In Sweden, the National Board of Health and Welfare issues national
guidelines setting out standards and recommended models of care for
major disease areas and medical conditions. These guidelines are the
main mechanism through which national government influences the
provision of health care and they are produced in different versions for the
medical profession, politicians and the public. Guidelines are developed
with professional bodies, thereby ensuring the buy in of key stakeholders.
The presentation on stroke care set out how the guidelines are being used
in Skane. At the same time, an inevitable consequence of decentralisation
is that it can be difficult to mainstream good practice, and the extent to
which it is appropriate for services to vary significantly between different
areas remains a key question for many decentralised systems.
2. Skane is one of two areas of Sweden in which the regional role has already been strengthened (although in other areas the county councils have a similar though less developed role). As in Denmark, participants in the study tour were struck by the prominence of the regional role in health care planning and in the organisation and management of health services. In Skane this was most evident (and most impressive) in relation to the reconfiguration of hospital services. Over a period of almost ten years, regional politicians have led a process that has now resulted in agreement that two hospitals should become specialist facilities, two others should provide a full range of acute services, and the remaining hospitals should provide planned care only.

3. It was recognised that change on this scale covering a population of 1.1 million could not have been achieved through action by the municipal councils (because they are too small and local) or by national government (because it is too remote and does not have the legitimacy and understanding of regional politicians). This raised a key issue for Wales about what exactly constitutes a ‘region’ and what role such an entity should undertake. For example, is the region Wales itself, or is there an intermediary role for a body somewhere in between local health and social care communities and the Welsh Assembly Government to take a lead on issues such as acute care reconfiguration? If so, do current regions have sufficient influence to be able to discharge such duties effectively?

4. Related to this, the quality of political leadership around health care issues was impressive. It appeared that regional politicians from different political parties in Skane were willing to work with each other and with local politicians (in the municipalities) to bring about necessary change, even in the face of public and professional opposition and at the risk of unpopularity. Certain features of the Swedish system, such as the staging of national, regional and local elections on the same day every four years, the maturity of the political system at the regional and municipal levels, significant local funding flexibility and the calibre of the people attracted into politics, contributed to the quality of political leadership. Again this raised a crucial issue for Wales about how best to engage local government in debates about health services, recognising that both the NHS and local government have a key role to play if services are to promote well-being and independence.

5. The reconfiguration of hospital services in Skane had been framed as an issue related to the quality of care and patient safety. This had enabled the regional politicians leading the process to make a claim to the moral high ground and to counter opposition by pointing out the disadvantages of maintaining the status quo. This emphasis on quality of care holds important lessons for the NHS in Wales.

6. Visits to health care facilities undertaken during the study tour confirmed that delayed transfers were no longer a significant issue in Sweden and that the policy of expecting municipal councils to pay for hospital care when a patient was deemed to be ready for discharged had been
responsible for this (the same applied in Denmark). The staff from hospitals and social care whom we met were of the view that this policy worked well (we did not have the opportunity to seek the views of local politicians and to understand the effect of the policy on their budgets and priorities). More generally, the philosophy (if not always the practice) of joined-up services seemed to be generally accepted and embedded in practice. In many cases, practitioners seemed not to view multi-professional working as a threat to their status and autonomy, but to recognise that joint working could strengthen and enrich their distinctive professional contribution.

7. The visits to health care facilities provided valuable insights into the efforts being made to strengthen the coordination of care, especially for older people. A number of projects are seeking to improve links between care provided in hospital and the community, with GPs having direct access to beds and social care staff working closely with hospital staff to strengthen transition from hospital to home (or in some cases nursing homes and short stay rehabilitation facilities). It appears that in Skane there has been a move away from residential care to home care with municipal councils paying for the cost of adaptations to facilitate care at home.

8. The value of generalism in the care of older people was underlined by some of the visits. In both Malmo and Lund, general physicians/geriatricians play a major role in hospital care of older people and coordinate the contribution of their specialist colleagues as well as links with GPs and social care staff and services. This has resulted in the implementation of a model of care that involves quick access to hospital beds when necessary, followed by rapid diagnosis, treatment and discharge (and short hospital stays as a consequence).

9. Some of the challenges identified in Skane were difficulties in recruiting doctors to work in primary care, long waits for patients to see a GP for non-urgent needs (in some cases leading to the use of the hospital emergency room to circumvent primary care), and the continuing challenge of achieving integration of services provided in hospitals, primary care and social care. Also, while progress is being made in giving higher priority to chronic diseases, it seems that politicians and the public are still strongly focused on acute hospitals and their role in the system. There is a health coordinating committee in Skane that links the region and the municipal councils and this is an important mechanism for promoting closer integration.
Lessons from Denmark

The Danish System

The Danish health and social care system is primarily tax-based, with a strong tradition of public service, universal coverage, decentralisation and high levels of patient satisfaction. With a population of just over 5 million, Denmark is a constitutional monarchy with a parliamentary system based on elections every four years (based on a system of proportional representation). The country has a strong tradition of public welfare provision and of decentralisation, with the financing and provision of primary and secondary care delegated to regional and local level under legislation of 1970. Despite high satisfaction with services, health outcomes are worse than in Sweden, with, for example, average life expectancy at birth of 76.9 (compared to 79.9 in Sweden and 78.1 in the UK).

During the 1990s, Denmark witnessed an acceleration of policy reform, with strong emphasis placed on increasing productivity and quality, reducing waiting times, free choice of hospital and activity-based hospital financing. From 1st January 2007, moreover, the system has experienced significant structural change, with the abolition of tax-raising powers at regional level, a merger of many regional and municipal organisations, and a greater role for municipalities in developing preventative and rehabilitative services. For a system accustomed to relative stability, this was a profound change (and the implications of the new system were being worked through as we visited). These changes have also been introduced only after significant political disagreement, and this again is rare in Denmark (where there is often a tradition of developing political consensus around major policy change).

Under the new system, the number of regional authorities has been reduced from 14 counties to 5 regions (from 0.6 to 1.6 million inhabitants), while the number of municipalities has been reduced from 271 to 98 (37% of the new municipalities have 50,000+ inhabitants, 28% have 30-50,000, 18% have 20-30,000 and 7% have under 20,000). Both levels are governed by directly elected politicians. The main function of the regions is now to run hospitals, while municipalities are responsible for most other health and social care services.

To ensure co-ordination between the region and municipalities, binding health agreements set out responsibilities for tasks such as hospital discharge. To try to ensure that municipalities have a financial incentive to develop preventative services, they are expected to make activity-based contributions to the cost of acute care (although many question if these incentives are strong enough or whether municipalities have the expertise to deliver on this important agenda). At a national level, the National Board of Health and central government focus primarily on regulating, supervising and financing, although there is now a growing role for central planning of some services.

The Study Tour
During a two-day visit, the study tour was hosted by the Department of Health Services at the University of Copenhagen. After an initial introduction to the Danish system and its approach to long-term conditions, participants broke into three groups to attend a series of half-day site visits (with each group visiting two sites). These included:

- A hospital-based cardiac rehabilitation unit
- A community-based health centre
- Two municipality health and social care services
- A general practice with a commitment to long-term conditions
- The National Board of Health and the Ministry of Health

During these visits, participants explored a range of issues relevant for Wales, including:

- The respective roles and contributions of the local authority, the region and the centre.
- The relationship between health and social care.
- Mechanisms and incentives for trying to develop care closer to home.
- The importance of political leadership, clinical engagement and the decentralisation of decision making.

**Key Lessons and Questions**

With the Danish system in the process of moving from one structure to another, the study tour offered the opportunity not only to ask some critical questions of Danish health and social care, but also to apply these to participants’ own organisations and to the Welsh system. In particular, key lessons and questions included:

1. In the past, policy co-ordination and system reform has tended to take place through a process of consensus, trust and cultural agreement, rather than through management hierarchy, inspection, performance management and/or market-based relationships. While this can take significant time, subsequent changes felt more bottom-up and consensual than in the UK (where change can sometimes feel imposed from above) and seemed to participants to incur fewer transaction costs in the long-run. Perhaps as a result, there seemed to be a greater sense of focusing on service delivery, on quality and on outcomes, rather than on more bureaucratic issues of process. At the same time, services also seemed concerned with the whole person (and there was concern that disease-specific pathways in a Welsh context might sometimes detract from seeing the person in the round). Above all, this approach was felt to lead to a situation in which it seemed possible to take appropriate risks and try something different, with little evidence of a blame culture.

2. Historically, Denmark has had a strong regional tier of government, democratically elected and with tax-raising powers. Despite recent
changes, regions arguably still have a key role to play in issues such as economic development and acute care reconfiguration, and the best way of organising the relationship between local, regional and national seems set to be a key issue as the new system beds down.

3. Participants visiting the National Board of Health were impressed by the role of the centre in developing standards, guidelines and frameworks (often with significant involvement from relevant professional bodies), setting the overall context in which decentralised services can be designed and delivered.

4. During several site visits, there seemed to be extremely impressive and forward-thinking political leadership at a local level. Although it is difficult to tell in a different system, it is conceivable that the relative autonomy enjoyed by the municipalities had the potential to encourage high calibre political leadership.

5. Participants found it strange that there was very little mention of health service public and patient involvement mechanisms. However, in a local government-led system, there is arguably less need for separate ‘involvement’ structures since local people and service users are ‘involved’ directly via their local taxes and via their vote. In many ways, this represents a very different notion of citizenship than in the UK, where the relationship of health care bodies in particular to the local population has often been questioned.

6. Despite a growing recognition of the need to support people with long-term conditions, political and media attention seemed still to focus on the quality of acute care. As a classic example, one of our speakers, the former Director of the National Board of Health, had recently resigned over a waiting times scandal in cancer care, yet it was hard to imagine a similar figure ever being asked to resign over a lack of preventative or rehabilitative services. Similarly, the University itself was based in a former acute hospital, and when this closed there were public and media protests. In contrast, there seemed little public outcry about the slow speed with which a network of community health centres was developing. For many participants, this raised similar questions about what health and social care services in Wales could do to make sure that the growing commitment to long-term conditions becomes part of mainstream political debate and is accepted and understood by the public and the media.

7. In spite of the recent reforms, there appeared to be insufficient levers and incentives in the Danish system to rebalance the system away from its current focus on acute care. In particular, the municipalities found themselves in a situation where they were paying a contribution towards the cost of hospital care and were tasked with developing community alternatives, yet exercised no control whatsoever over the people who make the decisions to refer to and admit to hospital. Again, this raised key questions about the extent to which the correct levers and incentives existed in Wales to prioritise care for people with long-term conditions.
8. Several of the projects visited seemed to exist because of the commitment and vision of individual clinicians, rather than because of the system as a whole. These then seemed vulnerable should the individual move on, and prompted a question about the extent to which the Welsh system encourages, supports and builds on the contribution of clinical champions (and how these contributions can be captured for the system as a whole).

9. In several projects, there was a growing questioning of the extent to which medical practitioners were best placed to deliver on the long-term conditions agenda. In one municipality, a regeneration scheme had achieved impressive results with a local community as a result of a tenant advisor approach (with a keyworker appointed to work with the local community, identify and respond to community concerns, act as a local resource etc). This person was not from a health or social care background at all, and their personal values and interpersonal skills appeared more important to the success of the scheme that any formal professional training. This then raised the issue of who may be best placed to take a lead in the Welsh long-term conditions agenda, and about the skills and values needed by such workers in the future.

10. In several examples, there was frustration with the recent reforms and a degree of pessimism about the extent to which they will be successful. However, at times, this appeared to stop individual practitioners and organisations from changing what was within their power to change. An example here was one of the municipalities visited which was critical of some of the recent reforms, but which had not yet grasped the opportunity to bring together its own workforce to develop more integrated care at local level. Thus, despite being responsible for both social and community health care, the municipality still had separate social work, home nursing, physiotherapy and OT teams, with little apparent attempt to integrate these or to develop single assessment or shared records. This then raised an issue, wider than the Danish system alone, about how best to focus practitioners and local organisations on working proactively and constructively on those things that they can change, rather than feeling inhibited by those that they cannot.
Practical Applications of Lessons Learned

Overall, the tour confirmed much that is positive in current Welsh policy and practice, whilst also raising some key challenges for the future.

Building on lessons from the study tour, participants have since returned to their local health and social care communities, and are now developing a series of practical projects to improve services for people with long-term conditions. These include:

- The reprovision of a community hospital and the development of a new model of community-based care.

- A project to boost the role of GPs in preventing hospital admissions, maximise local community provision, fast-track people in and out of hospital, and improve the ‘pull’ out of hospital.

- A project to identify and maintain the independence of older people at risk of deterioration.

Over time, lessons from these projects will be disseminated by NLIAH in order to share learning more generally.