

# Chronic illnesses in Swedish primary health care: Use of evidence based best practice and information technology

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## Abstract

The purpose of this study was to identify opportunities for improvement in managing chronic illnesses in primary care by gathering data about the use of evidence-based care processes and information technology in Swedish primary health care. The method used was a questionnaire mail survey to all Swedish primary health care centres with similar questions to those used for in a national survey of USA primary care organizations. A high proportion of the responding primary care centres in Sweden reported not using a number of evidence-based processes or being aware of these. The highest use of each care process was reported to be for diabetic patients, with slightly less use for asthma patients, and less for congestive heart failure patients, and the least use for patients with depression. The clinical information technology system capability is high in Sweden, but little used to aid management of chronic illness. There are significant variations between centres in their use of effective practices and information technology. This and other knowledge from this study can inform strategies to improve quality of care and reduce costs for managing chronic illnesses.

Key words: quality, evidence based medicine, chronic illness, primary care, information technology

## Introduction

There is an increasing incidence of chronic illness and rising costs for providing care for chronic or long term illnesses in the Nordic countries. There is also evidence of under-diagnosis, under-treatment and of failure to use primary and secondary prevention<sup>i,ii</sup>. It has been shown that more care could be provided in primary care settings, resulting in fewer hospital admissions, reduced costs and more timely and effective care<sup>iii</sup><sup>iv</sup>. Research shows certain organisational and clinical processes can improve care for people with long-term illnesses. A Cochrane review describes effective uses of disease registries for chronic disease management and prevention<sup>v</sup>. There is also good evidence that case management, usually by specialist nurses, improves outcomes for patients with congestive heart failure (CHF), diabetes, and mixed co-morbidities<sup>vi</sup>. Clinical guidelines can improve physician management of a number of chronic conditions and may improve clinical outcomes, if they are implemented in specific ways with effective types of education and/or reminder systems<sup>vii,viii</sup>.

There is also growing evidence that education in disease self-management for patients can result in better outcomes. This was found by randomized controlled trials with patients with different chronic diseases<sup>ix,x</sup> with diabetes,<sup>xi,xii</sup> and for patients with asthma in a Cochrane review<sup>xiii</sup>. Research shows that medical practice can be improved in different ways with performance feedback to physicians<sup>xiv</sup>

and that programme integrating interventions may be effective<sup>xv</sup>.

There are programmes for managing chronic diseases in the USA and UK that draw on this evidence and experience, including the Kaiser Permanente model, the Evercare model, other UK NHS programmes<sup>xvi</sup> and the "Wagner" Chronic Illness Care Model (CICM<sup>xvii,xviii</sup>). These programmes vary in the number of interventions they use, the evidence of their effectiveness, and in their purpose: some focus on reducing unnecessary hospital admissions and reducing costs. They are based on assumptions rather than research evidence that a combination of evidence based interventions will be more effective. It is also thought that clinical information technology in primary care can contribute to improvements in care for these patients.

A programme of research was started in 2000 in the USA to study the use of evidence based chronic illness management processes including computer care management systems in primary health care. This paper below reports the results of a Swedish study using a survey and interviews similar to the USA study and which considered practices used to care for people with chronic heart failure, diabetes, asthma and severe depression. The studies drew on the above research as well as other sources to identify 16 actions that were likely significantly to improve care for patients with chronic illnesses, termed "care management processes"<sup>xix</sup>. These actions

include the use of disease registries; practice guidelines for treatment; population disease management (a programme which identifies the patients, provides a symptom management and treatment plan and education); case management (to intensively manage patients with uncontrolled or high cost conditions); and health promotion and prevention for the disease. The US research also aimed to discover which practices had most effect on outcomes and whether combinations were more effective.

Questionnaires to gather data on the use of IT and these care management processes were developed and national surveys carried out in the USA and in Sweden in 2005. There is no published knowledge about which of these processes are practiced by physicians or their organisations in Sweden, or of their use of information technology. This information could help to decide whether actions are needed to improve care for chronically ill patients, which care processes need to be strengthened and how best to do so.

## Methods

The purpose of the study was to discover the extent to which Swedish physicians use care management processes and information technology in ways which have been found to result in effective care for people with chronic illnesses. The US survey of heads of primary care organisations was used as a basis for the Swedish mail survey of medical heads of all primary health care centres. The USA survey was originally developed using a re-

view of the literature on health care quality improvement, the dimensions of the US Assessment of Chronic Illness Care model<sup>xx</sup>, feedback from the national advisory committee to the study, as well as comments from a focus group of 9 medical directors from physicians organisations. The survey was revised after a pilot test with 36 medical groups and 10 independent practice associations (IPAs) and then used in the 2001 USA study<sup>xxi</sup>. The questionnaire was then extended for a follow up study in 2005. This questionnaire, slightly adapted for the mostly-public Swedish health system, was translated, back-translated and refined and piloted in one Swedish practice, using standard comparative research methods<sup>xxii</sup>. The English version of the questionnaire is reproduced in the full report<sup>xxiii</sup>. It asked the head to give information about their centre's use of information technology, effective care processes for long term conditions, quality activities, performance reporting and financial incentives, prevention and health promotion and organisation culture. The questionnaires were analysed using SPSS to assess how many services reported carrying out each of the "good practices in chronic illness management" and the results presented in tabular and pie chart form.

In Sweden a 49% response rate (n=440) was achieved from the total of 907 centres. An analysis of 100 responders and 100 non-responders found a small bias towards more of the larger centres replying: those responding on average had 4.5 doctors (and

9145 patients) and the non-responders 4.1 Doctors (and 8429 patients). Eighty percent were government owned, 8% were owned by private for profit organisations, and 7% were owned by one or more doctors. A separate interview study of 5 Stockholm centres was carried out to investigate what interviewees considered the barriers and enablers to make more use of in-

formation technology in their care for patients with chronic illness.

## Findings

The full Swedish findings are presented in a report which can be downloaded over the internet <sup>(xxiii)</sup> and are summarised in tables 1 and 2.

Table 1: Sweden-USA comparisons of care practices

	Replies from 49% of Swedish primary health care centres (PHCs)
<b>Patient lists including clinical data (disease registries)</b>	
Patients with diabetes listed.	60%
Asthma patients listed	31%
Congestive heart failure patients listed	20%
Patients with depression listed	14%
<b>Case Management</b>	
Nurse to coordinate and improve the quality of care for patients with diabetes	80%
Nurse to coordinate and improve the quality of care for patients with asthma	58%
Nurse to coordinate and improve the quality of care for patients with congestive heart failure	18%
Nurse to coordinate and improve the quality of care for patients with depression	7%
<b>Feedback to physicians about quality of care</b>	
Diabetes	
Asthma	61%
Congestive heart failure	30%
Depression	18%
	13%
<b>Clinical guidelines with reminders</b>	
Diabetes	35%
Asthma	18%
Congestive heart failure	14%
Depression	10%
Financial incentives received by the organisation	11% of PHCs for patient satisfaction

Table 2: Clinical information technology capability and use for managing chronic illnesses

Use of clinical IT by primary care physicians	Replies from 49% of Swedish primary health care centres (PHCs)
Standardised problem list	94%
Progress notes	93%
Medications prescribing	78%
Medications ordering reminders and/or drug interactions information	61%
Laboratory results	94%
Radiology results	52%
Electronic medical records	94%
Email exchange	4%
Tests and procedures	94% Laboratory 52% Radiology
Diagnosis and treatment outcomes	89%
Computerised entry of drug prescriptions	78%
Health history	94%
Automated reminder	30%

## Discussion

### Study Limitations

The study is limited by the 49% response rate, and by not knowing some important characteristics of the non-responders. This could mean the findings are not representative of the whole of Sweden: non-responders may have differed in terms of range of patient conditions cared for, population demography and other characteristics which might be relevant for understanding the quality of care for people with chronic illnesses across Sweden. Four chronic conditions were selected and it is possible that other chronic conditions may have been managed in a significantly different way. The data collected were anonymous reports by heads of the centres who, although practising clinicians at these centres,

may have limited knowledge about the daily practice of all the personnel at the centre. They may be biased towards presenting a positive rather than negative picture of their, especially about work on quality improvement.

Although the care management processes and IT elements have been shown in previous research to contribute to better quality outcomes, it cannot be assumed that following these in Sweden result in better outcomes for these populations. Assessment of compliance with best practice processes should be combined with assessment of outcomes, not least to build knowledge of process-outcome influences, but this was not possible in this study.

However, with these limitations in mind, the findings do provide the first broad picture of some aspects of how four chronic illnesses in primary care were managed in Sweden in 2005.

### **Overview**

Overall the research found a high proportion of primary care centres in Sweden did not use some practices or IT functions which were available in their IT systems or could easily be made available. This shows there is a potential to improve the quality of care for these patients. In most cases, improvements would save money for the county health systems which finance and manage both hospital and primary care. Further regional analysis could be undertaken to enable counties to target interventions to specific shortfalls of their PHCs in comparison the ideal performance.

### **Opportunities for improvement**

A comparison of the findings with a possible 100% compliance, as well as with the US study suggests the greatest opportunity for improvement appears to be in the following subjects:

Specialist education and roles: the interviews revealed that a significant hindrance was the lack of specialist knowledge in, or available to, primary care centre about prevention and care for specific chronic conditions. Basic education for centre staff, supported by chronic care specialists covering a number of centres is needed, and specialists could help set up systems for prevention and care as well as advising on specific patients.

Use of nurse care coordinators: 80% of Swedish health care centre reported using nurse care coordinators for most diabetic patients and 58% for most asthma patients, but this contrasts with 18% of centres reporting this care process for most patients for congestive heart failure and 7% for most patients with depression. As this care process is already established in Sweden in most centres, there may be benefits in extending it to other chronic diseases. This conclusion is supported by comparison with the USA data which shows 44% of primary care units use nurse care coordinators for congestive heart failure (compared to Sweden's 18%) and 23% for depression (compared to Sweden's 7%)<sup>(xix)</sup>

Education and information: 6% of heads reported knowing of the Wagner chronic care model or similar models. Education about the benefits of evidence based care for these conditions and of using IT in specific ways is a necessary, but not sufficient, action to improve care.

Priority, incentives and motivation: both public and private heads and doctors received little benefit for setting up systems to provide the types of care processes considered in this study. For most heads of services, their county purchasers or managers have not prioritised this patient group and there are many other competing priorities for their time. For private doctors and services, most financial savings made from their investment in computer and other systems would be made by the wider county of which

they are a part, and over the long term. Comparison with the USA (and UK) shows the potential for careful use of financial incentives and grants for system development to overcome this obstacle, but in a way which is compatible with the fact that doctors are already paid to provide the highest quality of care to these and all patients.

Proactive prevention: 2% of centres used and acted on risk assessment questionnaires. This is in marked contrast to the high use of risk assessment questionnaires and follow up action reported in the USA studies. Greater use of risk assessment for chronic disease with proactive prevention could be of benefit but would need the education and specialist support noted above.

Quality improvement: Some findings show there is scope to make more use of quality methods and patient data to improve care, including data about patients' complaints, and more use of e-mail by doctors to communicate with patients. These suggest possible organizational interventions to enable, encourage, and reward improvements. However, these data may also signal problems in the extent to which quality is prioritised and services are "patient centred". "Patient centred care" is respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions. Part of the problem may be lack of good measures of this aspect of service, and that providers are not asked to report specific measures, only to provide a

general annual report on quality. The use of these measures could be used as one aspect of developing more patient centred care, especially if it were carefully related to incentives.

IT based registers: Swedish PHC has some of the highest levels of computerisation in the world. It is therefore notable that there is a relatively low use of electronic lists of patients which includes clinical data for patients with different chronic diseases (47% reported such electronic registries for diabetes, and 13% for patients with depression, with asthma and CHF ranging between these two extremes). Creating such lists would be relatively easy and could significantly help to improve management of these patients.

IT system development: IT capability was relatively high, apart from depression, and nearly 80% reported electronic medication prescription ordering. However, decision support was not well-developed in many systems, such as easily accessible guidelines, and reminders or prompts during consultations. Results and reports from hospital departments were not available electronically in most cases, and 50% never use emails with patients. The interview findings highlighted barriers to making better use of IT: most electronic medical records were developed by hospitals and were not easy to use for chronic care management. There are 5 common systems in use which cannot be connected between centres or units. Investment in developing IT systems to support prevention

and chronic care management could result in savings for counties and for private primary care providers. This is supported by comparison to USA data which shows that, whilst far fewer primary care units have clinical IT capability, when systems are installed a far greater use is made of their potential for clinical care<sup>(xxi)</sup>. Swedish health systems, unlike many USA systems, have not driven greater use of the IT in which they have invested, or given incentives to primary care to “share the rewards”, which would accrue mostly to the county.

## Conclusion

The study gives information useful for Sweden and for other public health systems to develop national and local strategies to improve chronic illness management. It also provides a questionnaire and interview schedule to allow others to investigate the use of IT and effective methods on their region's primary health care, and to make comparisons with Sweden and the USA.

The high proportion of primary care centres in Sweden not using or knowing about some practices shows the potential to improve care for these patients. The opportunities for improvements appear to be greatest in the management of chronic depression, increased use of incentives, in health promotion and clinical IT, as well as more organised programmes of care to maximise the mutually reinforcing effects of individual care management processes. Specific improvements which also may be relevant to primary

care in other countries were described. These were in education and information, specialist education and roles, the use of nurse care coordinators, developing incentives and motivation, patient risk questionnaires and action, IT based registers, IT system development, and quality improvement actions including better measurement, accountability and incentives.

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Svensk sammanfattning

## Kroniska sjukdomar i svensk primärvård: Användning av evidensbaserade vårdprogram och informationsteknologi

Syftet med studien var att klarlägga förbättringsmöjligheter vid handläggning av kroniska sjukdomar i primärvården genom att samla in information om användningen av evidensbaserade vårdprogram och informationsteknologi. Metoden var en enkät som sändes per post till samtliga vårdcentraler i Sverige. Som förlaga användes en nationell enkät som riktats till primärvårdsorganisationer i USA. En betydande andel av vårdcentralerna meddelade att de inte använder ett antal specificerade vårdprogram eller var medvetna om dem. Vårdprogrammet för diabetes var det mest använda, medan vårdprogrammet för astma och hjärtsvikt utnyttjades något mindre. Depressionsprogrammet användes minst. Klinisk informationsteknologi är väl utbyggd i svensk primärvård men används sällan som ett hjälpmedel vid handläggning av patienter med kroniska sjukdomar. Variationerna mellan vårdcentralerna är stora vad gäller användning av vårdprogram och informationsteknologi. Denna och andra observationer i studien kan ge vägledning till strategier för förbättring av vårdkvalitet och effektivisering vid omhändertagandet av patienter med kroniska sjukdomar.