Value guided healthcare as a platform for industrial development in Sweden – feasibility study

Final Documentation

August 28, 2009

THE BOSTON CONSULTING GROUP
Project context – Background

Sweden has historically had a very strong reputation for its clinical research. Its importance for the country through contribution to a productive health care system as well as the development of both major BioPharma and MedTech companies is uncontested.

Over the past years several investigators have documented that Sweden's position in clinical research is deteriorating. The reasons are many and several excellent suggestions on how to address the situation have been proposed.

In 2008 a leading Swedish industrialist Carl Bennet gathered the 50 most senior leaders from Payers/providers, from Academia and Industry to discuss the situation and propose actions to Government. Aug 18 2009 the same group was invited to discuss a concrete proposal and plan for action. In preparation a BCG team was commissioned to assess the potential importance of Sweden's quality and patient registries. The team formulated a 10 year vision, translated this into a concrete governance model and a 10 year implementation plan. The project was jointly sponsored by AstraZeneca and Carl Bennet AB and executed during 10 weeks May-July, 2009.

A central insight in the project is that Health care in the Western countries needs transformational change in order to improve productivity and secure that the broader population can get access to high quality care and innovation. This transformation will not be successful if the motivation for clinical staff is efficiency and cost containment. In order to mobilize the base of the pyramid in the transformational efforts the focus has to be the quality of care for the patients.
Project context – Objectives

Define a 10-year vision for how Sweden could take a leading position internationally in value based healthcare

Define Sweden's current position in an international context, key strengths and barriers to change

Propose strategic priorities and estimate business case

Describe key actions, timeline and stakeholder actions required to deliver on strategy

Engage key stakeholders to test support and secure well founded recommendations
Executive summary

Providing high quality healthcare at reasonable cost is one of the most pressing issues facing industrialized countries today
- Unsustainable growth in spend across countries, exacerbated by current downturn
- Sweden with additional challenge from drop in clinical research and healthcare industry activity

Emerging health care "value paradigm" will increase industry productivity by focusing on outcomes/cost
- Cost-focus needs to be coupled with focus on outcomes to secure strong engagement by practicing clinicians in the required industry transformation
- Sweden with ~5 year head-start in new paradigm due to unique quality and patient registries

With shared vision and a coherent national strategy, Sweden could build world-leading platform in value-based healthcare within 10 years
- Positive and strong incentives to develop effective care for patients through transparency on performance
- Increasing clinical demand for innovation to improve care performance will enhance "translational" links between basic research and clinical practice
- Platform for industry to develop and test products meeting market requirements for healthcare productivity and safety

Swift action needed to leverage ~5 year window of opportunity
- Leadership by state and counties to define national strategy and provide seed financing
- Participation of all key stakeholders in defining policies, executing the strategy and realizing the vision
- Build national platform for quality registries while maintaining strong sense of ownership among clinicians
Current study scope holistic – integrating efforts by many

Large interest in outcomes but lack of shared vision, clear leadership and coordination

...but all agree coordinated efforts are lacking

"We see huge potential and we are realizing some, but we lack a joint vision to work towards"

"We have seen definite cases of ‘turf wars’"

"We’re afraid all these uncoordinated efforts can cause fatigue and make us lose momentum"

Scope of study to bring efforts together towards common vision and roadmap

Concrete and realistic 10-year vision with healthcare system perspective
- Ambitious but tried and tested
- Anchored in international outlook

Current landscape, vision and roadmap discussed with all key stakeholders
- >70 interviews
- Proposal built on strengths of current model

Roadmap allowing for paced implementation
- Interdependencies few but important
- Providers and other stakeholders can contribute independently

System perspective outlines one of the most attractive future industry platforms for Sweden

Source: Stakeholder interviews April – June 2009, BCG analysis
This material contains copies of slides prepared by members of The Boston Consulting Group, Inc, for the seminar "Sweden as the international leader in outcome based healthcare", held in Gothenburg August 18th, 2009. A list of all the participants at the seminar can be found in Appendix.

The slides are incomplete without accompanying oral commentary

The market and business case estimates contained in this presentation are based upon standard methodologies using public data, market interviews and assumptions derived from the insight gained during the project and data entrusted to The Boston Consulting Group (BCG). BCG has not independently verified all of the data and assumptions used in these analyses. Changes in the underlying data or operating assumptions will clearly impact the analyses and conclusions.
Agenda

Starting position

Shared vision and value captured

Way forward

Appendix
Unsustainable growth in healthcare spend

1. Average nominal wage index

Note: Index on basis of local currency; Per capita HC cost 2006 at exchange rate of 1 USD=0.797 €, 2005: 110.22 Yen/US$
Source: OECD Health Data 2008; EIU
Sweden's strength in healthcare increasingly challenged

Sweden losing clinical trial volumes

Drop in registered patents

Medically trained students shrinking share of Medical faculty PhDs

1. At Uppsala University, Karolinska Institutet; Lund University and Gothenburg University
Note: CAGR=Compounded Annual Growth Rate
Source: Klinisk forskning – ett lyft för sjukvården, Läkemedelsverket; SCB; Teknikområdesbarometern 2006-2008 PRV; BCG Analysis
Improving healthcare easier said than done

Source: The Economist
Value based healthcare new paradigm emerging

Outcome metrics, eg:
- Mortality
- Mobility
- Pain sensation
- Activities in daily life
- Post-op infection

\[
\text{Outcome} \quad \frac{\text{Cost}}{} = \text{Value}
\]

- Measured as outcomes, not inputs
- Defined around patient, not supplier
- Measured over full cycle-of-care

Source: Institute of Strategy and Competitiveness, Harvard Business School; BCG analysis
Value focus win-win for all stakeholders

**Payers & Providers**
- Transparency on outcomes
- Improved quality of care
- New decision-support tools
- Pay for value delivered
- Effective patient choice

**Academia**
- World class outcomes research
- Future clinical research hub
- Unlocking potential in translational medicine

**Patients**
- Best possible outcome...
- ... at minimal cost

**Industry**
- Unique platform for outcomes based safety, efficacy and pricing studies
- New healthcare information services industries

Source: BCG analysis

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Sweden with strong starting point in quality registries

69 quality registries started to date¹

>20 registries with >85% patient coverage

1. Only including registries receiving funding from SKL
Source: "National Healthcare Quality Registries in Sweden 2007"; Grant applications; BCG analysis

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10 registries stand out for exceptional level of quality

Note: See Appendix for detailed registry example
Source: SKL, registry annual reports, registry grant applications to SKL; BCG analysis
First-class quality registry fulfill six requirements

1. **Strong core team**
   - One team responsible
     - Clear process leadership
     - Personal dedication
     - Sense of ownership
   - Strong support from specialists
     - Data collection is team effort
   - Entrepreneurial "can-do" spirit
     - creating winners

2. **Committed specialists**
   - Atmosphere of cooperation
     - Evidence-based discussion
     - Mutual respect and team spirit
     - Peer pressure in joint efforts
   - Evidence-based approach
     - Strong foundation in research
     - Willingness to measure

3. **Valid & reliable metrics**
   - Strong foundation in research
     - Internationally tested metrics
     - Proven causality
     - Possible to benchmark
   - In touch with clinical practice
     - Practicality filter
   - Risk adjustment possibilities
     - Collect relevant patient data

4. **Systematic feedback**
   - Fast feedback of results
     - To allow comparisons over time for own results
   - Learnings linked to feedback
     - Learn from others
     - Workshops and seminars
     - Organized best-practice sharing

5. **Easy-to-use IT interface**
   - Easy to enter data
     - Only collect what is needed
     - Easy-to-use IT interface
     - Move towards integration with EMR systems
   - Easy to receive feedback
     - Fast feedback of own results
     - Decision-support tools

6. **Stable financing**
   - Access to stable financing
     - Backing from institutions
     - Clearly delineated budget for registry admin, maintenance
   - Arms-length relationships with private financiers
     - Access to funding without compromising data integrity

Source: BCG analysis
~25% of HC-costs already covered by registries

1. Analysis based on KPP-data
2. Assumptions: Share captured same as for inpatient with adjustment for clinic coverage; for registries covering outpatient care, clinic coverage is same for inpatient and outpatient
3. Quality registries for diabetes, leg ulcer and heart failure cover primary care; assumptions: cost/patient and visit 2000 SEK, 4 visits/year for diabetes patients; cost/patient and visit 2000 SEK, 52 visits/year for leg ulcer patients; cost/patient and visit 4000 SEK, 4 visits/year for heart failure patients
4. Only existing quality register for psychiatry is eating disorder; assumption cost/patient and year 200000 SEK; 1355 patient registered in RIKSAT 2007

Note: Not including cost of pharmaceuticals, dental care, political activities and restructuring activities
Source: KPP-database; SKL; annual reports for quality registries, grant applications to SKL; BCG analysis and estimates
Today national quality registries cover 41% of specialized inpatient cost

Note: Cost data covers specialized inpatient somatic care
Source: KPP-database; SKL; annual reports for quality registries, grant applications to SKL; BCG analysis

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Unique platform from broad range of personal registries

Medical outcomes data
- SKL-funded quality registries
- Other quality registries – E.g; child cancer

Personal ID number
620510-XXXX

- Epidemiology
- Comparative effectiveness
- Health economics
- Longitudinal studies
- ...

Mandatory patient data
- Socialstyrelsen registries

Drug usage data
- Socialstyrelsen registry

Socioeconomic data
- Statistics Sweden

Genetics data
- Biobanks

Other data

Solid patient integrity absolute requirement

1. e.g. medical birth, birth defects, (eg MFR)
Agenda

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Appendix
A shared 10 year vision for Swedish healthcare

Swedish healthcare system envy of world

In the past 10 years Sweden has emerged as the leading nation in value based healthcare and personalized medicine. Today, Swedish physicians and nurses work interactively with outcomes analysis and decision-support tools to deliver world-class healthcare results for their patients. The Swedish healthcare system displays several unique characteristics:

- Clinical researchers have access to some of the best data sources in the world. Many important clinical breakthroughs have been made over the last years by teams integrating comprehensive clinical outcomes data with high quality data from national population and cost registries.
- Swedish patients and their relatives are empowered to make informed care choices based on the quality of care. Outcomes information services provide transparent performance data for all providers in the country.
- Sweden is the fastest nation in the world in making valuable new drugs available to their population. The Swedish MPA (LV); the Dental and Pharmaceutical Benefits Agency (TLV) and clinical research competence centers work closely together to define how to best assess the value of conditionally registered products and efficiently determine appropriate reimbursement levels.
- Sweden is the pharmaceutical and medical technology industries’ country of choice for conducting post-approval safety, efficacy, and cost-benefit studies. This has been one of the key factors that have enabled a reinvigoration of the Swedish life-science industry.

In addition to the clinical benefits, focusing on value based healthcare has saved the Swedish taxpayer ~50 BSEK in reduced direct medical costs. No wonder Sweden is being flocked by researchers from other countries eager to learn how outcomes and cost measurements can lead to world class research and clinical care.
Swedish experience suggests that vision is realistic

Examples for all stakeholders on following pages
Better quality of care without increasing payer cost
Quality versus cost of healthcare in Swedish county councils 2008

No significant correlation between quality and cost identified

Note: Cost including: primary care, specialized somatic care, specialized psychiatry care, other medical care, political health- and medical care activities, other subsidies (e.g. drugs)
Source: Öppna jämförelser, Socialstyrelsen 2008; Sjukvårdsdata i fokus 2008; BCG analysis
~1.5% annual savings in HC-costs conservative estimate of results of outcomes work

<table>
<thead>
<tr>
<th>Example</th>
<th>Medical category</th>
<th>Source of saving</th>
<th>Annual savings¹</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduction of hip arthroplasty re-operations from elimination of risk factors</td>
<td>Surgery</td>
<td>Best-practice sharing</td>
<td>1.5 – 2.0%</td>
<td>Hip-prosthesis registry</td>
</tr>
<tr>
<td>Reduced amputation frequency from systematic selection of patients for distal bypass surgery</td>
<td>Surgery</td>
<td>Prevention</td>
<td>1.0%</td>
<td>Swedvasc</td>
</tr>
<tr>
<td>Reduction in stroke readmission from secondary-preventive activities</td>
<td>Acute</td>
<td>Prevention</td>
<td>1.5 – 2.0%</td>
<td>Patientregistret / Socialstyrelsen</td>
</tr>
<tr>
<td>Reduction of chronic disease prevalence and complications from early identification of risk factors</td>
<td>Chronic conditions</td>
<td>Prevention</td>
<td>3.0%</td>
<td>Pitney Bowes / Harvard Business School</td>
</tr>
<tr>
<td>Overall medical cost savings from adoption of health information technology²</td>
<td>Overall</td>
<td>Patient-data analysis that supports medical practice</td>
<td>3.0%</td>
<td>RAND Corporation / The Economist</td>
</tr>
</tbody>
</table>

Transparency drives best practice sharing (I)
Example: Cardiovascular disease

Karlstad central hospital

- Care cycle redone
- PCI\(^1\) -unit established
- Emergency care expanded to 24/7 coverage

Ranked #43 of 73 hospitals

"We felt ourselves that our care was insufficient. We pushed for improvements in cardiac care in Värmland for many years, but nothing happened [until the results became transparent]

-Unit mgr Karlstad Hosp.

Quality index\(^3\) raised from 1 to 8, 30-day mortality reduced by 50%
Ranked #22

1 year mortality 20%,
Ranked #68 of 73 hospitals

Halmstad hospital

- Care aligned with national treatment guidelines\(^2\)
- New specialist departments for specific coronary conditions started
- Staffing improved

"[The media] was an alarm clock. Thanks to the statistics we received a lot more resources and could see what others did that we did not do."

-Hospital mgr Halmstad Hosp.

Quality index raised from 1 to 4
Mortality reduced by 50%
Ranked #45

1. Percutaneous coronary intervention
2. on angiography and PCI
3. Riks-HIA
Source: SVT.se; Aftonbladet 2007-03-08; DN 2009-05-06; Dagens Medicin 2008-08-26; Läkartidningen nr 44 vol. 104, 2007; Värmlands Folkblad 10 Oct 2007
## Transparency drives best practice sharing (II)
### Example: Birth injury

<table>
<thead>
<tr>
<th>Starting point</th>
<th>Actions</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ryhov hospital ranked #31 of 47 hospitals in 2003</td>
<td>Staff trained on procedures</td>
<td>National ranking dramatically improved:</td>
</tr>
<tr>
<td></td>
<td>Cooperation between physicians and midwifes improved</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Strong commitment from staff</td>
<td></td>
</tr>
</tbody>
</table>

"We could see that we were behind and felt that we wanted to do something about it"

"All statistics have been continuously displayed on a board in the clinic, it has been important that everyone could follow the development"

- Unit manager Ryhov Hospital

![Image of medical staff](image.png)

Clinical improvements:
- Sphincter injury: 13.7 → 5.6%
- Perineotomy¹: 20% → 5%

¹. Surgical incision of the perineum during birth

Quality registries significant source of clinical research

10 short-listed registries important source of research

~400 publications / year conservative estimate of future potential

1. # of publications for 10 short listed quality registries in 2007
2. Average number of publications per short-listed registry 2007 multiplied by number of registries (59)
3. Adding 31 new quality registries to capture a larger share of total HC-cost

Note: Total number of publications in clinical medicine: 4,000 / year; Total number of dissertations in medicine: 900 / year
Source: Högskoleverket & SCB 2008; KLiniks forskning – ett lyft för sjukvården 2009; registry annual reports, registry grant applications to SKL; BCG analysis
Great industrial value from late-stage registries

Evolution of quality registry use

- Higher quality of care and lower variance in outcomes through best practice sharing
- Clinical research feeding into and benefiting from quality registries

Clinical research

Quality of care studies and best practice sharing

Platform for product development and evaluation

Reduced outcome variance makes registry attractive platform for e.g. product development
- Easier to evaluate effect

Large industry applications potential
- Definition of unmet medical need and willingness to pay
- Post-marketing safety and efficacy studies
- Cost-benefit studies

Source: BCG analysis
Treatment convergence facilitates testing of new therapies

Less side-effects (astigmatism) in laser eye surgery over time and lower variance

Induced astigmatism through laser eye surgery, average and variance (# of dioptres)

Significantly lower inflammation levels for rheumatoid arthritis patients and lower variance in outcomes

Average RA CRP value

1. Dipotre = measured as average change of dioptre per clinic based on individual patient data
2. CRP-C = reactive protein level in blood indicating level of inflammation. Lower level of CRP indicates lower level of inflammation short-term as well as lower risk for inflammation long-term
3. National coverage 56% while Falun coverage is 100% for all types of RA-patients. Since 1997 Falun has measured and followed-up all its RA-patients on a monthly basis. Data has been used for regional quality work.

Source: Cataract Annual Report 2007; RA Annual Report 2008-09
Rheumatoid Arthritis registry already reaping full benefits

Example of value of late-stage registry

RA registry driving projects in all registry application areas

Concrete value for all stakeholders – RA registry capturing full registry value

- Covering significant patient cost: ~1.5 BSEK / year
- Registry interface used in therapy
  - Patient tracking own progress through online application
- Attracting 3rd party financing: ~40x public financing
- Opening up new research areas
  - Large-scale longitudinal epidemiological studies
- Industry using registry to validate new therapies
  - eg, TNF-α inhibitors

Source: Rheumatoid registry, Interview with Lars Klareskog, BCG analysis

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However, immediate action needed to keep ~5 year advantage

**US projected health IT investments**

<table>
<thead>
<tr>
<th>Year</th>
<th>US projected health IT investments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>0</td>
</tr>
<tr>
<td>2011</td>
<td>5</td>
</tr>
<tr>
<td>2013</td>
<td>15</td>
</tr>
<tr>
<td>2015</td>
<td>20</td>
</tr>
<tr>
<td>2017</td>
<td>10</td>
</tr>
</tbody>
</table>

**European examples**

- **Sundhedsvalitet**
  - "Objective to support the free choice of care and encourage patient involvement...through providing comparable information on quality and service for the country’s hospitals"

- **NHS**
  - "Quality indicators are helping to drive improvements in primary and community care"

- **AOK**
  - "Through peer-review processes we have decreased mortality for several of our clinics"

- **Schön Kliniken**
  - "We strongly believe in measuring outcome, and will continue to adjust and fine tune our current model"

*Source: "National Healthcare Quality Registries in Sweden 2007", CSC Healthcare; The Economist, BCG analysis*
Agenda

Starting position

Shared vision and value gained

Way forward
  • Governance model
  • Business case
  • Roadmap and milestones

Appendix
8 main principles to reach vision and unlock value

1. All registries patient and disease focused capturing outcomes over care-cycle across provider organizations

2. Significant increase in data availability while maintaining highest patient integrity

3. All registries used to identify quality of care best practice and drive continuous improvements of care. Data use for academic and industrial studies is at the discretion of registry leaders

4. All main stakeholders jointly govern registry infrastructure

5. Registry base funding is secured long-term

6. Better data usage and registry support through shared resources with expertise and tools

7. Registry – industry – regulator (LV and TLV) interfaces are formalized to ensure transparent and efficient relationships

8. Harmonization of registry IT infrastructure and EMR data entry processes is prioritized

Source: BCG analysis
Governance structure engine for stakeholder value capture
Infrastructure and expertise for evidence-based methodology and processes

Payers & Providers
- Outcomes analysis and reporting
- Structured best-practice sharing
- Process improvement expertise

Academia
- Interface for researchers and financiers
- New research topics
- In-house analysis expertise

Industry
- Interface for study design
- Sales of registry studies
- Information services solution opportunities

Patients benefit from increased transparency and better quality of care through all stakeholder activities

Source: BCG analysis

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Striking a balance between central scale and local leadership

**Steering Committee**
- SKL/Landsting
- SoS
- LV
- TLV
- Registry rep
- Patient rep
- UMC\(^1\) rep
- Academia rep
- Industry rep

**Executive body** (initially PMO role)
- National oversight and coordination
- Strategy and policy definition
- Basic quality registry funding
- Central audit function

**Competence Centers (∼6)**
- Data use interface and services
- Data analysis services
- Facilitate best practice sharing
- Information technology (IT)

**Quality Registries**
- Data use interface and services
- Data analysis services
- Facilitate best practice sharing
- Information technology (IT)

**Providers**
- Universities
- Licensing (LV)
- Reimbursement (TLV)
- Industry

**Populations registries (EpC, SCB etc)**

- Skilled care and population
- Coordination and strategy
- Basic quality registry funding
- Central audit function
- Executive body for assessments, implementation, follow-up

- Data use interface and services
- Data analysis services
- Facilitation of best practice sharing
- IT infrastructure and support
- Coherence in data, metrics

- Metrics definition and data capture
- Registry management

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1. University Medical Center
   Source: BCG analysis

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Proposed funding mechanism balances base funding and rewards to attractive registries

Industry

Private funding for specific registry study, if approved by registry owners

Steering committee

Annual direct registry funding conditional on participating in open comparisons through one CoCe

Competence Center (CoCe)

50% of surplus from study to specific registry for registry-related activities

Funding used for registry administration, buying services from CoCe

50% of surplus allocated by CoCe to other registries that can show need for additional financing

Fee-for-services

Quality registries

"Development funding"

"Base funding"

1. After reimbursing study specific costs at Competence Center and at registry in question
2. provided by Socialstyrelsen

Source: BCG analysis
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Appendix
Business case example: proposed investments with >10x payback in medical cost only next 10 years

Value based model driving annual savings of ~1.5% in medical costs...

...equaling >10x direct medical cost payback

~56 BSEK in total savings over 10yrs, while delivering higher quality of care

Total required investment of ~5 BSEK over same period
- Registry funding, building competence, IT, etc.

10.8x multiple of money coming 10 years

Estimates of societal value at least ~3-5x higher than direct medical cost savings

1. Based on benchmarks
Source: SCB, BCG analysis
**Annual costs for establishing governance model**

~350-550MSEK

<table>
<thead>
<tr>
<th>Registry base funding</th>
<th>Competence centre seed funding</th>
<th>Executive body, PMO and audit function</th>
<th>Required IT- for complete EMR-solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annual basic funding per registry 4 MSEK</td>
<td>Initial cost related to resources within competence centre</td>
<td>Executive body / PMO</td>
<td>Quality IT investments complementary to national IT strategy initiative</td>
</tr>
<tr>
<td>09 10 11 12 13 14 15-18</td>
<td>2010: 3 Centers (excl Uppsala)</td>
<td>2009-2013: 30 MSEK</td>
<td>Total required investment across time period: ~600 MSEK</td>
</tr>
<tr>
<td>Annual direct outlay (MSEK)</td>
<td>2011-2012: 5 Centers</td>
<td>2014-18: 20 MSEK</td>
<td>Audit function</td>
</tr>
<tr>
<td>0 100 200 300 400 500</td>
<td>Annual direct outlay (MSEK)</td>
<td>2010: 5 MSEK</td>
<td>2010: 5 MSEK</td>
</tr>
</tbody>
</table>

Note: All figures in real numbers
Source: BCG analysis

**Graphs**

- Annual direct outlay (MSEK)
- Executive body / PMO
- Audit function
- Quality IT investments complementary to national IT strategy initiative

**Total required investment across time period: ~600 MSEK**
Agenda

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Appendix
Four-step approach to realize vision and capture value

Strengthen foundation

- Negotiate governance, financing
- Establish PMO
- Set targets, deadlines
- Identify legal obstacles

Ramp-up

- Establish shared capabilities, resources
- Define IT infrastructure
- Drive legal changes

Expansion

- Reach full data use infrastructure

2009

2012

2019

Full value capture

Functional initiatives

- Negotiate governance, financing
- Establish PMO
- Set targets, deadlines
- Identify legal obstacles
- Define IT infrastructure
- Drive legal changes

Registry initiatives

- Push for full registry coverage
- Start new registries

1. Program Management Office overseeing national initiative
Source: BCG analysis

In the past 10 years, Sweden has emerged as the leader in value-based healthcare and personalized medicine. Today, Swedish physicians and nurses work interactively with outcomes analysis and decision-support tools to deliver world-class healthcare results for their patients. The Swedish healthcare system displays several unique characteristics:

- Clinical researchers have access to some of the best data sources in the world. Many important clinical breakthroughs have been made over the last years by teams integrating comprehensive clinical outcomes data with high-quality data from national population and cost registries.
- Swedish patients and their relatives are empowered to make informed care choices based on the quality of care. Outcomes information, ensures patient transparency and performance data for providers.
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- Sweden is the pharmaceutical and medical technology industries' country of choice for conducting post-approval safety, effectiveness, and economic studies. This has been one of the key factors that have enabled the new Swedish life-science industry.

In addition to the clinical benefits, focusing on value-based healthcare has saved the Swedish taxpayer ~50 BSEK in reduced direct medical costs. No wonder Sweden is being flocked by researchers from other countries eager to learn how outcomes and cost measurements can lead to world-class research and clinical care.
Need for immediate actions to secure momentum in 2-3 yrs

Strengthen foundation

- Set up Steering Committee
- Secure registry financing
- Push for wider CoCe mandate
- Identify what additional CoCe(s) to start
- Run IT framework project
- Initiate legal change (primary care reporting)

Ramp-up phase

- Drive key registry initiatives
  - Set goals for current registries lacking coverage
  - Support start of additional key registries

Establish PMO¹ to drive initiative

Negotiate governance setup, key targets and milestones

2009 2010 2011 2012

¹ Program Management Office

Source: BCG analysis

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Proposed IT integration process allows for paced implementation

Today’s double-entry inefficient and significant obstacle to full registry coverage

- Cumbersome and fault-prone for professionals
- Blocking primary care from full registry participation

Integrating user interface for EMR¹ and quality registries pragmatic approach for improvement

- National format specifications defined for select quality metrics in EMR interface
- Full patient data sent to EMR, select metrics sent simultaneously to quality registry

Reduced implementation risk when providers can choose when to move to integrated solution

¹. Electronic Medical Record
Source: BCG Analysis
Implementing registry initiatives would give coverage of 57%.

<table>
<thead>
<tr>
<th>Tax-funded healthcare costs (%)</th>
<th>Full coverage in existing registries → 57% coverage</th>
<th>Additional 6% coverage from adding key diagnoses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td>37%</td>
<td>63%</td>
</tr>
<tr>
<td>Outpatient</td>
<td>77%</td>
<td>23%</td>
</tr>
<tr>
<td>Primary care</td>
<td>82%</td>
<td>18%</td>
</tr>
<tr>
<td>Psychiatry</td>
<td></td>
<td>57%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>43%</td>
</tr>
</tbody>
</table>

1. Analysis based on KPP-data
2. Assumptions: Share captured cost same as for inpatient
Note: Not including cost of pharmaceuticals, dental care, political activities and restructuring activities
Source: KPP-database; SKL; annual reports for quality registries, grant applications to SKL; Läkartidningen; peer-review journals; BCG analysis and estimates
Key milestones to make 10 year shared vision reality

<table>
<thead>
<tr>
<th>Strengthening Foundation &amp; Ramp-up</th>
<th>Expansion</th>
<th>Full value capture</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>2012</td>
<td>2015</td>
</tr>
</tbody>
</table>

**Ramp-up phase completed**
- ~40% of healthcare cost covered by registries
- All governance, capabilities components initiated
- IT framework established
- All new registries in start-up phase
- Primary care reporting to patient registry

**Well into expansion phase**
- ~55% of healthcare cost covered by registries
- All governance, capabilities components fully resourced
- EMR interface integration near completion
- Target registry coverage somatic care

**Realizing full value capture**
- ~60% of healthcare costs covered by registries
- Full data use ensured through active Competence Centers
- Full EMR interface integration for quality reporting
- Target registry coverage all care cycles
- World-leading commercial applications
Agenda

Starting position

Shared vision and value gained

Way forward

Appendix
Steering Group, Reference Group, Interview list and Meeting participants
## Steering and reference group members

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carl Bennet</td>
<td>Ordförande i Getinge, Göteborgs Universitet</td>
</tr>
<tr>
<td>Anders Ekblom</td>
<td>Vice-President Development AstraZeneca</td>
</tr>
<tr>
<td>Maria Anvret</td>
<td>Professor FRCPath, forskningspolitisk talesperson Svenskt Näringsliv, ledamot IVA</td>
</tr>
<tr>
<td>Sigbrit Franke</td>
<td>Rådgivare till Umeå &amp; Stockholm Universitet, tidigare Universitetskansler</td>
</tr>
<tr>
<td>Claes Ånstrand</td>
<td>Tidigare statssekreterare och landstingsråd</td>
</tr>
<tr>
<td>Gunnar Alvan</td>
<td>Tidigare GD Läkemedelsverket</td>
</tr>
<tr>
<td>Göran Sandberg</td>
<td>Rektor Umeå Universitet</td>
</tr>
<tr>
<td>Kjell Asplund</td>
<td>Tidigare GD Socialstyrelsen</td>
</tr>
<tr>
<td>Marie Beckman Suurkula</td>
<td>Sjukhusdirektör Akademiska sjukhuset tillika biträdande landstingsdirektör</td>
</tr>
<tr>
<td>Joakim Dillner</td>
<td>Professor, forskare</td>
</tr>
<tr>
<td>Anna Hedborg</td>
<td>Tidigare stadsråd och GD</td>
</tr>
<tr>
<td>Nina Rehnqvist</td>
<td>Professor, ordförande i SBU</td>
</tr>
<tr>
<td>Göran Stiernstedt</td>
<td>Direktör, avd. chef vård och omsorg SKL, tidigare biträdande landstingsdirektör</td>
</tr>
<tr>
<td>Ulf Wahlberg</td>
<td>Vice President, industri research relations Ericsson</td>
</tr>
<tr>
<td>Gunnar Nemeth</td>
<td>Managing Director and Chief Operating Officer Capio Group</td>
</tr>
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>70 interviews – Sweden's starting position (I)

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
<th>Company</th>
<th>Date</th>
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</thead>
<tbody>
<tr>
<td>Marie Beckman Suurküla</td>
<td>Hospital Director</td>
<td>Akademiska Sjukhuset Uppsala</td>
<td>May 28</td>
</tr>
<tr>
<td>Kristina Pernvi</td>
<td>VP Global Regulatory Op.</td>
<td>Astra Zeneca</td>
<td>May 29</td>
</tr>
<tr>
<td>Frederic Sachs</td>
<td>VP Clinical T</td>
<td>Astra Zeneca</td>
<td>June 16</td>
</tr>
<tr>
<td>Olle Björk</td>
<td>Generaldirektör</td>
<td>Barncancerfonden</td>
<td>Jun 03</td>
</tr>
<tr>
<td>Sören Johansson</td>
<td>VP Business development</td>
<td>Elekta</td>
<td>Jun 16</td>
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<tr>
<td>Ulf Wahlberg</td>
<td>Vice President</td>
<td>Ericsson Industry research relations</td>
<td>Jun 11</td>
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<tr>
<td>Gunnar Persson</td>
<td>Register manager</td>
<td>Gall-Riks (gallstone) – Jönköping</td>
<td>May 07</td>
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<tr>
<td>Johan Malmqvist</td>
<td>CEO</td>
<td>Getinge</td>
<td>Jun 12</td>
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<tr>
<td>Per Båtelsson</td>
<td>CEO</td>
<td>Global Health Partners</td>
<td>May 29</td>
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<tr>
<td>Patrik Sobocki</td>
<td>Head of Pricing / Market Access</td>
<td>GSK</td>
<td>Apr 27</td>
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<tr>
<td>Johan Thor</td>
<td>Medical Doctor</td>
<td>Högskolan i Jönköping / KI</td>
<td>May 04, Jun 10</td>
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<td>Göran Karlström</td>
<td>Register responsible</td>
<td>Intensive care (SIR) – Karlstad</td>
<td>May 07</td>
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<tr>
<td>Linus Jönsson</td>
<td>CEO</td>
<td>i3Innovus</td>
<td>Jun 1</td>
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<tr>
<td>Niclas Adler</td>
<td>Managing Director &amp; Dean</td>
<td>Jönköping International BS</td>
<td>May 07</td>
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## >70 interviews – Sweden's starting position (II)

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<tr>
<td>Göran Henriks</td>
<td>Development director</td>
<td>Jönköpings LL – Qulturum</td>
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</tr>
<tr>
<td>Anita Aperia</td>
<td>Professor Pediatrics</td>
<td>Karolinska Institutet</td>
<td>Jun 04</td>
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<tr>
<td>Bo Angelin</td>
<td>Professor Clinical Metabolism</td>
<td>Karolinska Institutet</td>
<td>Jun 04</td>
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<tr>
<td>Anders Ekbom</td>
<td>Professor Epidemiology</td>
<td>Karolinska Institutet</td>
<td>Jun 24</td>
</tr>
<tr>
<td>Lars Klareskog</td>
<td>Professor rheumatology</td>
<td>Karolinska Sjukhuset Solna</td>
<td>May 13</td>
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<tr>
<td>Mats Lundström</td>
<td>Registry Manager</td>
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<tr>
<td>Martin Neovius</td>
<td>Researcher</td>
<td>KI-Centre for Pharmacoepidemology</td>
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<td>Richard Bergström</td>
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<td>Alicia Lycke</td>
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<td>Christina Rängemark – Å</td>
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<td>Läkemedelsverket</td>
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<tr>
<td>Gunnar Alvan</td>
<td>Former Director General</td>
<td>Läkemedelsverket</td>
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<tr>
<td>Nils Feltelius</td>
<td>Medical Doctor</td>
<td>Läkemedelsverket</td>
<td>May 05</td>
</tr>
<tr>
<td>Joakim Dillner</td>
<td>Prof. of Virology Molecular Epid.</td>
<td>Lunds U. Dep.of Medical Microbiology</td>
<td>May 28</td>
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<tr>
<td>Eva Leach</td>
<td>Project leader</td>
<td>Nationella Patientöversikten</td>
<td>May 07</td>
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<tr>
<td>Johan Brun</td>
<td>Medical director</td>
<td>Pfizer</td>
<td>Apr 29</td>
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>70 interviews – Sweden's starting position (III)

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<tr>
<td>Lars Påhlman</td>
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<td>Rectal cancer – Uppsala</td>
<td>May 19</td>
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<tr>
<td>Anna Hedborg</td>
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<td>Riksförsäkringsverket</td>
<td>May 28</td>
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<tr>
<td>Sari Wallin</td>
<td>Register coordinator</td>
<td>Riks-Stroke – Norrlands US</td>
<td>May 06</td>
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<tr>
<td>Sten Walther</td>
<td>Registry chairman</td>
<td>SIR</td>
<td>May 25</td>
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<tr>
<td>Nina Rehnquist</td>
<td>Chairman SBU:s nämnd</td>
<td>SBU</td>
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<tr>
<td>Pär Sundström</td>
<td>IT manager</td>
<td>Sjukvårdsrådgivningen</td>
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<tr>
<td>Åke Karlsson</td>
<td>Responsible for KPP</td>
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<tr>
<td>Göran Stiernstedt</td>
<td>Head of Division</td>
<td>SKL</td>
<td>Aug 11</td>
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<tr>
<td>Roger Molin</td>
<td>Ass.head of Health/Soc care iv</td>
<td>SKL</td>
<td>May 15</td>
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<tr>
<td>Ann Hedberg Balkå</td>
<td>Department Head</td>
<td>SKL</td>
<td>Jun 16</td>
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<tr>
<td>Bodil Klintberg</td>
<td>Registry responsible</td>
<td>SKL, e-health</td>
<td>Jun 5</td>
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<tr>
<td>Karin Johansson</td>
<td>State Secretary</td>
<td>Socialdepartementet</td>
<td>Aug 11</td>
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<tr>
<td>Sara Johansson</td>
<td>Department Secretary</td>
<td>Socialdepartementet</td>
<td>Jun 24</td>
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<tr>
<td>Tobias Nilsson</td>
<td>Political Advisor</td>
<td>Socialdepartementet</td>
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<tr>
<td>Elisabeth White</td>
<td>Research coordinator</td>
<td>Socialdepartementet</td>
<td>Aug 11</td>
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>70 interviews – Sweden's starting position (IV)

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<tr>
<th>Name</th>
<th>Role</th>
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<tr>
<td>Henrik Lundström</td>
<td>Topic Expert</td>
<td>Socialdepartementet</td>
<td>Aug 11</td>
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<tr>
<td>Jesper Olsson</td>
<td>Special Advisor</td>
<td>Socialdepartementet</td>
<td>Jun 24</td>
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<tr>
<td>Anders Åberg</td>
<td>Head of Statistics division</td>
<td>Socialstyrelsen</td>
<td>May 18</td>
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<tr>
<td>Karin Nyqvist</td>
<td>Researcher</td>
<td>Socialstyrelsen</td>
<td>Jun 10</td>
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<td>Kjell Asplund</td>
<td>Former Director General</td>
<td>Socialstyrelsen</td>
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<tr>
<td>Mona Heurgren</td>
<td>Director</td>
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<td>May 18</td>
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<tr>
<td>Mona Boström</td>
<td>County Council Director</td>
<td>Stockholms Läns Landsting</td>
<td>June 26</td>
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<td>Ulf Stenestrand</td>
<td>Register manager</td>
<td>Swedeheart – Linköping</td>
<td>May 08</td>
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<tr>
<td>Jonas Malmstedt</td>
<td>Register manager</td>
<td>Swedvasc – KI</td>
<td>Apr 28</td>
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<tr>
<td>Peter Fritzell</td>
<td>Register group member</td>
<td>SweSpine (back surgery)</td>
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<td>Maria Fagerqvist</td>
<td>Medical Researcher</td>
<td>TLV</td>
<td>May 07</td>
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<tr>
<td>Thord Redman</td>
<td>Coordinator</td>
<td>TLV</td>
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<tr>
<td>Peter Lönnroth</td>
<td>Director</td>
<td>Region Västra Götaland</td>
<td>Aug 10</td>
</tr>
<tr>
<td>Göran Sandberg</td>
<td>Vice-Chancellor</td>
<td>Umeå University</td>
<td>Jun 9</td>
</tr>
<tr>
<td>Bertil Lindahl</td>
<td>Professor</td>
<td>Uppsala Kliniska Forskningscenter (UCR)</td>
<td>May 26</td>
</tr>
</tbody>
</table>

The Boston Consulting Group
# >70 interviews – International benchmarking

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<th>Name</th>
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<th>Company</th>
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<tbody>
<tr>
<td>Lisa Van Maasakkers</td>
<td>Head Quality mgmt</td>
<td>Schön Kliniken</td>
<td>Apr 30</td>
</tr>
<tr>
<td>Roland Brandmeier</td>
<td>Medical Doctor(^1)</td>
<td>Schön Kliniken</td>
<td>May 5</td>
</tr>
<tr>
<td>Caroline Powell</td>
<td>CEO</td>
<td>Picker Institute</td>
<td>May 11</td>
</tr>
<tr>
<td>Alexander Kirstein</td>
<td>CFO</td>
<td>Universitätsklinikum Eppendorf</td>
<td>May 4</td>
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<tr>
<td>Joe Foley</td>
<td>Director Business Dev.</td>
<td>Cleveland Clinic</td>
<td>Apr 30</td>
</tr>
<tr>
<td>Tom Wadsworth</td>
<td>Administrative Director</td>
<td>Cleveland Clinic</td>
<td>Apr 30</td>
</tr>
<tr>
<td>Raymond Baxter</td>
<td>SVP Community Benefit</td>
<td>Kaiser Permanente</td>
<td>Jun 12</td>
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<td>Alide Chase</td>
<td>SVP Quality and Service</td>
<td>Kaiser Permanente</td>
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<tr>
<td>Jennifer Baron</td>
<td>Research public health</td>
<td>Harvard Business School</td>
<td>Apr 24</td>
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<tr>
<td>Philipp Ostwas</td>
<td>CFO</td>
<td>Klinikum Rechts der Isar</td>
<td>May 4</td>
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<tr>
<td>Gunnar Nemeth</td>
<td>CEO</td>
<td>Capio</td>
<td>May 18</td>
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<tr>
<td>Dr. Mansky</td>
<td>Medical doctor</td>
<td>Helios</td>
<td>May 15</td>
</tr>
<tr>
<td>Gene Nelson</td>
<td>Director for quality administration</td>
<td>Dartmouth-Hitchcock</td>
<td>May 21</td>
</tr>
<tr>
<td>Dr. David Dreis</td>
<td>Medical director of quality outcome</td>
<td>Virginia Mason</td>
<td>May 11</td>
</tr>
</tbody>
</table>

## Site visits

- Schön Kliniken\(^2\)
- Cleveland Clinic\(^3\)

---

1. Former head of the department and advisor; 2. One day site visit, incl. discussions with 3 physicians; 3. One day site visit, incl. discussions with quality personnel and 2 physicians
Gothenburg 18 Aug – Meeting participants (I)

Regeringen
• Karin Johansson, statssekreterare Socialdepartementet

Akademi
• Professor Karin Markides, rektor Chalmers
• VMD. Johan Carlsten, vicerektor Chalmers
• Professor Pam Fredman, rektor Göteborgs universitet
• Professor Olle Larkö, dekanus vid Sahlgrenska akademien
• Professor Harriet Wallberg-Henriksson, rektor Karolinska Institutet
• Professor Karl Tryggvason, dekanus för forskning på KI
• Professor Peter Gudmunson, rektor KTH
• Professor Mathias Uhlén, KTH
• Professor Mille Millnert, rektor Linköpings universitet
• Professor Björn Gerdle, prodekan Hälsouniversitetet
• Professor Bo Ahren, dekanus medicinska fakulteten Lunds universitet
• Professor Göran Sandberg, rektor Umeå universitet (referensgrupp)
• Professor Anders Hallberg, rektor Uppsala universitet

Regioner - landsting
• Sören Olofsson, regiondirektör region Skåne
• Anders Thulin, medicinsk direktör region Skåne
• Hannie Lundgren, forskningschef region Skåne
• Thorbjörn Ekström, FoUU-direktör Stockholms läns landsting
• Marie Beckman-Suurkula, sjukhusdirektör Akademiska sjukhuset Uppsala (referensgrupp)
• Jack Lysholm, chef för FoUU-staben Västerbottens läns landsting
• Peter Lönnroth, biträdande hälso- och sjukvårdsdirektör Västra Götaland
• Martin Magnusson, utvecklingsdirektör Östergötlands läns landsting
• Anders Heijl, FoU-samordnare Östergötlands lans landsting

Referensgrupp
• Professor Gunnar Alvan
• Professor Kjell Asplund
• Professor Joakim Dillner
• Anna Hedborg, tidigare statsråd

Utländska talare
• Professor Michael E. Porter, Harvard Business School
• Jens Deerberg – Wittram, Chief Operating Officer Schön Kliniken
Gothenburg 18 Aug – Meeting participants (II)

**Forskningsföreträdare, forskningsrådgivare och myndighetsföreträdare**
- Professor Maria Anvret, forsknings- och innovationschef Svenskt Näringsliv
- Michaël Berglund, Managing Partner, Michaël Berglund Executive Search AB
- Professor Håkan Billig, huvudsekreterare ämnesrådet medicin Vetenskapsrådet
- Professor Sigbrit Franke, tidigare universitetskansler, rådgivare i forskningsfrågor
- Professor Lars Klareskog, ansvarig för RA-registret
- Docent Bertil Lindahl, ansvarig för kompetenscentrum (UCR) i Uppsala
- Professor Nina Rehnqvist, ordförande i SBU, Statens beredning för medicinsk utvärdering samt ordförande i delegationen för samverkan inom klinisk forskning (referensgrupp)
- Professor Olle Stendahl, Linköpings universitet
- Christina Rångemark Åkerman, GD Läkemedelsverket
- Claes Anstrand, tidigare statssekreterare Utbildnings- och kulturdepartementet

**Industri**
- Professor Jan Lundberg, Executive Vice President, Global Discovery Research AstraZeneca
- Anders Ekblom, Executive Vice President, Global Drug Development AstraZeneca
- Martin Nicklasson, VD och koncernchef Biovitrum
- Gunnar Nemeth, koncernchef Capio (referensgrupp)
- Tomas Puusepp, VD och koncernchef Elekta
- Vice President Ulf Wahlberg, industry research relations Ericsson (referensgrupp)
- Peter von Ehrenheim, VD GE Healthcare AB
- Per Båtelson, VD och koncernchef Global Health Partner
- Magnus Öhman, VD St Jude Medical AB
- Johan Malmquist, VD och koncernchef Getinge
- Carl Bennet, styrelseordförande och huvudägare Getinge

**Boston Consulting Group (BCG)**
- Stefan Larsson, Partner and Managing Director
- Johan Öberg, Partner and Managing Director
- Rasmus Molander, Project Leader
- Peter Svensson Project Leader
Registry examples
GallRiks – Swedish quality registry on gallstone surgery

Registry example

Registration of biliary surgeries and endoscopic examinations of bile duct

From initial discussions to high coverage register in five years

<table>
<thead>
<tr>
<th>Initial discussions to start register in 2003</th>
<th>Start of register in 2005</th>
<th>&gt;90% hospital coverage ~90% patient coverage in 2008</th>
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</thead>
<tbody>
<tr>
<td>2003</td>
<td>2004</td>
<td>2005</td>
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</table>

History
- Initial discussions about need for a gallstone registry started in 2003, after many meetings to define metrics and anchoring in the profession the registry started in May 2005

Governance
- Run by the Swedish Surgical Society
- Steering group of 7 permanent and 5 deputy members, one national coordinator

Financing
- Grant from SKL 800 th SEK for 2009

Coverage
- Patient coverage 75% in 2007
- Hospital coverage 80% in 2007
- 8 999 cholecystectomy and 5 128 ERCP\(^1\) registered in 2007

Metrics
- Information on surgical intervention and postoperative course for patients
- Quality of life is measured before and after surgery

Reporting process
- Web-based reporting through corporation with UCR\(^2\)
  - After operation / examination physicians register in web tool
  - Patient surveys reported on paper and registered by local coordinator on each hospital
  - Local coordinator registers follow-up after 30 days, 6-9 months

Feedback process
- Annual report; with some health metrics by hospital
- Reporting physicians can see own results and hospital average
- Reporting hospitals can see their operating physician’s results

Key initiatives
- Will participate in “Open Comparisons” 2009

1. Endoscopic Retrograde Cholangiopancreatography
2. Uppsala Clinical Research and Registry Center

Source: Interview with registry manager; National Healthcare Quality Registries in Sweden 2007; SKL; annual report; grant application

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Swedvasc – Vascular Registry in Sweden

Registry example

Registration of peripheral vascular surgery

Development from small local registry to nationwide, high coverage registry

- Started in 1987 as local registry in Southern Sweden, registration on surveys ended in 2003, registry administrated at UCR since then, development of new database started in 2006, done by UCR, Swedvasc 2.0 launched in 2008

- Run by the Swedish Society for Vascular Surgery
- Steering group of 15 members, one coordinator

- Grant from SKL 900 th SEK for 2009

- Patient coverage 95% in 2007
- Hospital coverage 100% in 2007
- 10 166 operations registered in Swedvasc 2007

- Process metrics
  - Reason for intervention, type of surgery and graft, manufacturer

- Health metrics
  - Complications, function, infection, stroke, mortality

- Web-based reporting through corporation with UCR
  - Prior to procedure, after procedure, and follow-up after 30 days and one year
  - Reporting normally done by vascular surgeons, at some hospitals trained nurses take care of it

- Annual report; with some health metrics by hospital
- On-line analysis of own results and country average on web
- Down-loading of data for local analysis

- Launched Swedvasc 2.0, a new version of the registry, in 2008

1. Vascular Registry In Southern Sweden, Uppsala Clinical Research and Registry Center
Source: Interview; National Healthcare Quality Registries in Sweden 2007; SKL; annual report; grant application

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Riks-Stroke – National Quality Register for Stroke

Registry example

Registration of stroke

Registry for quality development in Swedish stroke treatment

- Started in 1994 on the initiative of Per-Olov Wester, 63% of all stroke caring units participated from beginning, 100% since 1998, web-based reporting since 2001

- Steering group with 6 members, working group with 6 members

- Grant from SKL 2.5 M SEK for 2009

- Patient coverage 82% in 2007
- Hospital coverage 100% in 2007
- 24,130 admissions registered in 2007

- Process metrics
  - Care on stroke unit, treatment with pharmaceuticals
- Health metrics
  - ADL functions before and after stroke, complications, survival

- Web-based reporting
  - Surveys filled in by care takers at occasion of hospitalization, one person on each hospital responsible for reporting in web module
  - 3 months follow-up of patient experienced data

- Annual report; with many health metrics by hospital
- On-line analysis of own results and county council average
- Participate in “Öppna jämförelser”

- Development of new IT-platform

Source: Interview; National Healthcare Quality Registries in Sweden 2007; SKL; annual report; grant application

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Swedish National Hip Arthroplasty Register

Registry example

Registration of total hip arthroplasty and partial arthroplasty

Second oldest registry, went web-based early

- Start of register in 1979, covered total hip arthroplasty
- Registry became web-based in 1999
- Start registration of partial arthroplasty in 2005

History
- Registry started in 1979, covered total hip arthroplasty from start, web-based reporting in 1999, measure patient reported variables since 2002, registration of partial arthroplasty started in 2005

Governance
- Board members, Johan Kärrholm, Göran Garellick, Cecilia Rogmark and Peter Herberts; steering group with 5 members
- Board and steering group is elected after consultation with Swedish Orthopaedic Association

Financing
- Grant from SKL 3.0 M SEK for 2009
- Support from Västra Götalandregionen

Coverage
- Patient coverage 96% in 2007
- Hospital coverage 100% in 2007
- 20,676 registrations in 2007

Metrics
- Process metrics
  - Implant type, surgical method, operation environment
- Health metrics
  - Pain, life quality, re-operation, survival after 2, 5 and 10 years

Web-based reporting
- Touch screen linked to registry's website to collect preoperative patient related metrics
- Surveys are used in follow-up, coordinator report on website

Feedback process
- Patient records from re-operations collected and analyzed
- Annual report; with many health metrics by hospital
- Participate in “Öppna jämförelser”

Key initiatives
- Start of registry center in the Västra Götaland region, will share IT-resources, statisticians and office space with NDR and Onkologiskt centrum

Source: National Healthcare Quality Registries in Sweden 2007; SKL; annual report; grant application
Swedeheart – Coronary heart conditions
Registry example

Registration of acute coronary care, secondary prevention, coronary angiography

Created by consolidating four registries in 08/09

| History | • Swedeheart created by consolidating acute coronary care registry, secondary prevention registry, coronary angiography registry and heart surgery registry in 2008
  • High and growing coverage in recent years |
|---------|----------------------------------------------------------------------------------|
| Governance | • Steering committee: Ulf Stenestrand, Kristina Hambraeus, Torbjörn Ivert, Anders Jeppsson, Monica Forslund, Stefan James
  • Four working committees covering four areas in registry |
| Financing | • Grant from SKL 4.3 MSEK for 2009, of which majority for competence center tied to registry
  • Additional financing via grants channeled through UCR on ad hoc basis |
| Coverage | • Patient coverage 98% in 2007
  • Hospital coverage 100% in 2007
  • 62,561 registrations in 2007 |
| Metrics | • Process metrics
  • Delay times, diagnostics, acute reperfusion, coronary artery x-ray, PCI use
  • Outcome metrics
  • Survival rate, symptoms, complications, lifestyle changes, medication, indicators of following national guidelines |
| Reporting process | • Web-based reporting
  • New IT infrastructure under development after consolidation of old registries
  • Attempt to build in decision-support functionality in registry, unclear legal consequences |
| Feedback process | • Annual report; with many health metrics by hospital
  • Participate in “Oppna jämförelser” |
| Key initiatives | • Several best-practice sharing initiatives organized via UCR competence center
  • Contributed heavily to Socialstyrelsen national report on coronary care published in March 2009 |

Source: National Healthcare Quality Registries in Sweden 2007; SKL; annual report; grant application, Mayo clinic

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Business case focuses on medical cost savings only

Three areas of value from outcomes work

1. Societal value
   - Medical cost savings
   - Reduced compensation for sick-leave
   - Reduced other compensations
   - Improved absenteeism
   - Improved presenteeism
   - Improved quality of life

2. Platform for life-science industry
   - Sweden as country of choice for value assessment of new products eg post-marketing studies and early launches
   - Increased innovativeness in medical system
   - New companies & products from translational medicine
   - New healthcare information services and decision support tools industries

3. Research revenue and publications
   - Increased revenues from clinical trials (industry above)
   - World class dissertations and articles on drivers of clinical outcomes

Focus for business case

Business case focuses on financial implications of implementing recommendations:
- Direct medical cost savings
- Required investments
- Required operating expenses

Business case shows that medical cost savings alone unambiguously justify investment in value guided healthcare
High level business case approach

Logic for business case

Cost reduction from outcomes work

Increased cost coverage by registries

Registry base funding

Establishing of CoCe1

Executive body, PMO, audit function

IT investment for complete EMR

Medical saving

Investment needs

Incremental reduction in healthcare cost

High level results

• 5% of healthcare costs eliminated by 2018

• Multiple of money²: 10.8x
  – Net cash flow ~50 BSEK

• NPV³ 09-18 ~34 BSEK
  – Total NPV ~250 BSEK

• Investment required 0.24% of annual healthcare spend
  – Accumulated spend 3.0% of 2008 healthcare spend

1. Competence Centers 2. Multiple of money = Accumulated savings/Accumulated costs 3. Discount rate of 6% assumed

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Baseline healthcare cost inflation rate estimated at 4.75%

Historic growth rate  
(1992 = 100)

SKL future estimate¹  
(2006 = 100)

BCG future estimate  
(2008 = 100)

1. SKL estimate assumes efficiency improvements from better use of IT-systems, org changes and unidentified other systematic improvements (no reference to specific initiatives/actions is made)

Source: OECD Health data 2008; SKL publication “Kommer vi att ha råd med sjukvården?” 2005
Outcomes work holds potential to reduce HC cost growth rate

Baseline yearly increase in healthcare costs (4.75%)

Expected annual cost reduction in areas covered by registries (1.5%)

Share of healthcare costs covered by registries

Annual growth in HC cost is reduced

Impact of proposed plan

Source: OECD Healthcare Cost 2008, BCG estimates
Savings to society 3-5x medical cost savings

Medical and societal savings

Comments

Savings to society from better health / reduced sickness well above medical costs
- Compensation for sick-leave¹
- Other compensations
- Absenteeism
- Presenteeism

Studies estimating total societal costs put value at 3–5 x medical costs:
- Obesity 4.4x
- Depression 5.0X
- Overall (Östergötland) 3.0X
- Overall (Healthways in US) 3.7x

¹ Sick-leave compensation mainly driven by psychological and musculoskeletal diseases
Source: IHE, Östergötland community council healthcare report 2007, Healthways, TLV

Societal saving max
Societal saving min
Medical cost saving

Backup
Logic for estimated cost for basic registry funding

IT costs

- Operational activities
  - IT-supply
  - Development/updates¹
  - Licenses/Software
  - Other²
  - 1,600-1,800 TSEK

Personnel cost

- Registry management
  - Metrics definition and data capture
  - Provide data analysis services
  - Coordinate outcome improvements across clinics
  - 1,800-2,000 TSEK

Other costs

- 2-4 Meetings/year
- Book
- Other
- 400-450 TSEK

Required base funding per registry ~4,000 TSEK

¹ Including cost for FTEs
² Follow-up, mobile internet

Note: All figures in real numbers
Source: SIR registry funding application, lönestatistik.se, BCG analysis and estimates

The Boston Consulting Group
Logic for estimated cost for establishing and strengthening competence centers

Personnel cost
- Statistician
- Study development
- Marketing
- Sales support
- Coop. with industry
- Coop. with health economics
- Legal expertise
- Financial expertise
- OH

Training
- Specific training

Office
- Rent
- IT
- Other

Backup

Note: All figures in real numbers
Source: UCR, BCG analysis and estimates

<table>
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<th>Year</th>
<th>Personnel cost</th>
<th>Training</th>
<th>Office</th>
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<td>2012</td>
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<td>~400 TSEK</td>
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</tbody>
</table>

Required funding/year:
- 2010: ~25,000 TSEK
- 2011: ~73,000 TSEK
- 2012: ~71,000 TSEK
Logic for increased registry coverage
Full patient coverage in existing registries gives 57% specialized inpatient cost coverage

Note: Cost data covers specialized inpatient somatic care
Source: KPP-database; SKL; annual reports for quality registries, grant applications to SKL; BCG analysis

Full coverage in existing registries increase cost captured from 41% to 57% (corresponding to 9.6 BSEK)

Key actions to increase coverage in current registries

Steering Committee communicates importance of quality registries
- Identify current obstacles and monitor progress

Make basic funding contingent upon joining competence center

Underline benefits to registries from having high patient coverage
- E.g. communicate private-funding logic

Share of specialized inpatient cost captured by quality registry (%)
Setting up new registries increases potential cost coverage to 63% in specialized inpatient care

Captured cost increases from 57% to 63% (corresponding to 4.2 BSEK)

Key actions to establish new registries

Appoint registry management
- Owner and management team

Define model for new registry
- Develop start-up action plan
- Choose which competence center registry will be member of

Define valid & reliable outcomes metrics
- Capture full care-chain
- Ensure metrics are anchored in profession

Ensure competence center support during establishment of registry

Note: Suggested diseases and disorders can constitute new quality registries, or merge with already existing registries
Source: Interviews; BCG analysis

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Addition of primary care in quality registries drives full care cycle coverage

Logic for expansion of quality registries to also cover primary care

Patient has to be in focus rather than HC-function
- Objective to enable tracking throughout care cycle
- Hence, expand registries to cover primary care, not establish one primary care registry that includes all diseases

Registries for chronic diseases initial priority
- Chronic disorders important part of healthcare
  - Significant share of total healthcare cost
  - Large share of primary care visits
- Limited quality improvement potential for routine diagnoses e.g., sinus infections, tonsillitis, urinary infections

Diabetes forerunner in registry primary care coverage
- 90% of all primary care clinics report into registry (900 clinics)

Pilot initiative for 4-5 chronic diagnoses first step towards including primary care in existing quality registries
- When pilot is up and running, expand to remaining chronic disorders

Proposed diagnoses for pilot initiative

1. Based on estimates of primary care cost
2. Based on patient coverage of registry

Source: Interviews, annual reports for quality registries, grant applications to SKL, BCG analysis and estimates
Psychiatry registry development to build on ongoing initiative

Ongoing initiative to have 9 psychiatry registers in place by 2011

Required actions

Ensure establishment of new competence center is aligned with proposed Competence Center structure

Detail ongoing initiative

- Plan including concrete goals and milestones
- IT interface
- Monitoring of initiative to ensure progress according to plan

Initiate effort to increase patient coverage in existing registries

- Define action plan
- Identify competences and resources needed to execute on plan
- Communicate importance and benefits of registries
- Monitor reporting compliance and act if insufficient

Establish new registries in areas

- Focus on maximizing cost capture

---

1. Specifications on portal: capacity to handle all national quality registries in psychiatry, existing as well as new registries; one single module for patient base information for all users, diagnosis specific quality registries connected to portal as separate modules

Note: RIKSÅT – Eating disorders, BipolåR - bipolar affective disorder, RUSA - severe adhd, PsykosR – psychosis, SBR – Svenskt Beroende Register, SÖK - Nationellt kvalitetsregister för barn och ungdomar som konstaterats/misstänks ha blivit utsatta för sexuella övergrepp, RättspsyK – Rättspsykiatriskt kvalitetsregister

Source: SKL, Socialstyrelsen, BCG analysis

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Detailed way forward – Roadmaps
Actions to get momentum coming 2-3 years and beyond

Program Management Office (PMO) / Exec. body

- Establish PMO
- Oversee key implementation projects
  - Prepare decision material for steering comm.
  - Follow up and provide guidance in key projects
- Executive body handling permanent tasks
  - Assessment, follow-up
  - Decision-support for SC

Functional initiatives

- Set up steering committee
- Initiate legal changes
  - primary care, patient data law
- Secure full registry funding
- Push for wider CoCE mandate
- Identify new CoCe to start and extend activities of existing CoCes
- Run IT framework project
- Implement new integrated IT solution
  - Paced implementation according to provider capabilities

Registry initiatives

- Set & meet coverage goals for current registries
- Start and get full coverage in additional registries

Source: BCG analysis
Initial roadmap defined through negotiation between state and counties, anchored with key stakeholders

1. Negotiation and agreement
   - (Modeled on ALF\textsuperscript{1} framework or similar)
   - Financing mechanism & level
   - Steering Committee setup
   - PMO\textsuperscript{2} mandate & organization
   - Initial roadmap

2. Financing

3. Steering Committee
   - SKL
   - LV
   - TLV
   - Provider rep
   - Academia rep

4. Program Management Office
   - Key functional initiatives
   - Key registry initiatives

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1. Avtal om Läkarutbildning och Forskning – Negotiated agreements between the state and select counties regarding co-financing for specialised medical education and research.
2. Program Management Office.
3. Potentially involving Letters of Intent from key stakeholders.
4. Potentially involving Vetenskapsrådet.

Source: Interviews with Claes Anstrand June 2009, BCG analysis
High level roadmap to develop the required functional areas

Governance
- Estab. PMO
- PMO – monitoring implementation process
- Exec. body – permanent SC support tasks
- Est. Steering Committee
- Nat. framework for stakeholder partnering
- Basic funding logic
- Establish additional CoCe
- Strengthening of existing CoCe

Resource/competence development
- Assess resource requirements
- Map competence and registry gap
- Appoint new reg. team, strengthen exist
- Gradual training / recruiting

Information technology (IT)
- Def. framework
- Adapt providers to integrated solution according to timeplan for compliance
- Develop decision-support tools for integrated solutions

Legal
- Require primary care to report according to DRG
- Revise law on patient data to allow real-time feedback
**Key milestones**

- Establish Steering Committee
  - Appoint members, define plan / vision

- Exec. body/PMO – monitoring implementation process
  - Frequent evaluation of progress relative to time plan
  - Overall prioritization

- Set up framework for conditional licensing & reimbursement
  - Test framework w. pilot

- Strengthening of existing CoCe
  - Create coherent vision
  - Set up objectives, time plans and resource needs

- Determine process for making outcome data public to patients

- Integrate regional cancer registries into new national CoCe-model

- Determine BP sharing process

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**Governance**

- PMO established
- SC established
- CoCe operating according to defined model
- National framew. for cond. licensing in place
- 6 CoCes established
- PMO phased out

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**Functional initiatives**

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1. Program Management Office
   Source: BCG analysis
Detailed roadmap for resource and competence development

Key milestones

2009
- Assessment of resource requirements for CoCe
- Identify areas of registries needed, appoint owner

2010
- Appoint team for new registries; ensure competence and resource distribution for existing registries; evaluate and strengthen resources and competence needed
- Mapping of competence need vs. availability

2011
- Define approach for adjusting resource pool
- Gradually educate / recruit new competences e.g. legal, finance, marketing and sales support

2012
- Build statistical and epidemiological expertise within CoCe

2013
- All required registries started

2014
- New CoCe / governance model fully in place

2015-20
- New CoCe / governance model fully in place

Source: BCG analysis
Detailed roadmap for IT and Legal

Key milestones

Information Technology (IT)

2009
Define framework, timeplan for integrated IT solution

2010
Adapt providers to integrated solution according to paced timeplan for compliance

2011
Develop decision-support tools for integrated solutions in collaboration with registry owners

2012
Change law to require primary care reporting into SoS patient registries

2013
Revise Law on patient data to enable e.g. individual feedback from quality registries and cross-referencing

2014

2015-20
Integrated EMR solution for all registries

Legal

Source: BCG analysis
High level roadmap to increase registry quality

- **Increase coverage in current registries**
  - Launch initiative
  - Define action plan
  - Monitor progress
  - Arrange BP-sharing meetings

- **Add new registries**
  - Assess new reg.
  - App. owner
  - Build registry
  - Monitor progress
  - Support process
  - Integrate cancer registries

- **Primary care**
  - Assign pilot “owner”
  - Develop action plan
  - Expand registry
  - Ensure full coverage
  - Develop evaluation process
  - Evaluation of pilot and give feedback
  - Develop IT interface solution
  - Expand pilot to all relevant areas in PC
  - Organize best practice sharing for registries

- **Psychiatry**
  - Launch initiative
  - Build registry
  - Define action plan existing & new reg.
  - Ensure full coverage existing and new reg.
  - Organize best practice sharing for registries

Source: BCG analysis
Detailed roadmap for increasing coverage in current registries

Key milestones

Increase coverage in current registries


- Launch coverage initiative
- Define action plan; id gaps & capabilities, resource needed
- Ensure full coverage for inpatient
  - Communicate importance and benefits of registries
  - Ensure compliance from clinics
- Specific initiative to ensure full outpatient coverage
  - Identify white-space
  - Communicate importance of participation
  - Ensure compliance from clinics
- Organize best-practice sharing meetings

Defined action plan for coverage increase
Full patient coverage in current registries, i.e. inpatient & outpatient

Source: BCG analysis
Detailed roadmap for establishing new quality registries

Key milestones

- 2009: Assess. of new reg needed. App. owners
- 2011: Develop individual action plan for new registry
  - Identify resources and competence needed
  - Identify metrics
  - Decide on CoCe-membership
- 2012: Build registry according to identified best-practice model
  - Ensure full coverage
- 2014: Organize BP sharing
- 2015-20: Integrate regional and national cancer registries for each diagnoses

All new quality registries launched
Cancer registries

>95% patient coverage for all registries, i.e. inpatient & outpatient

Source: BCG analysis

Registry initiatives
Detailed roadmap for including primary care in quality registries

Key milestones

2009

Assess. of pilot registries, appoint owner

2010

Develop plan for expansion of current registry to primary care
- Resources & competences
- Metrics

2011

Expand registries to primary care
- Communicate importance and benefits of participating

2012

Ensure full coverage in pilot
- Ensure compliance from clinics

2013

Develop process for evaluation of pilot

2014

Evaluate pilot and give feedback
- To pilot registries
- To expansion registries

2015-20

Identify expansion registries, appoint owner

Expand pilot to all relevant chronic disorders in primary care

Develop common IT-interface for primary care
- Same for all registries

Develop and implement common classification system for diagnoses and treatments in all primary care clinics

Source: BCG analysis

The Boston Consulting Group
Detailed roadmap for establishing psychiatry quality registries

Key milestones

Psychiatry

2009

Set detailed goals & milestones for expanded initiative

Define action plan for full coverage existing registries
  • Identify competence, resource needed

Identification of expansion registries, appoint owner

Ensure full cov. for existing registries
  • Communicate importance and benefits of registries
  • Ensure compliance from clinics

Develop action plan for new reg.
  • Resources and competence needed
  • Identify metrics

Build registry according to identified best-practice model

Ensure full coverage
  • Communicate importance and benefits of registries
  • Ensure compliance

Alignment of KPVi1 structure with new CoCe model

Organize best practice sharing

Full patient coverage existing registries

Full patient coverage for all registries

2010 2011 2012 2013 2014 2015-20

1. Kvalitet i Psykiatrisk Vård – Recently established CoCe for psychiatry. Source: BCG analysis