The role of governance in the integration of digital health solutions for chronic diseases in Swedish primary care?

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Abstract

Introduction: Chronic diseases is a significant and increasing burden, requiring a shift towards primary care at the center of providing integrated care. Digital Health Solutions (DHS) can have an important role to facilitate integrated care and to support the empowerment of patients. Sweden combines an ambitious agenda of digital health with being at the forefront of integrated care for chronic diseases. In spite of this, there is a limited utility of DHS in chronic diseases, providing an important setting to analyze how the role of governance may impact in the utility of DHS.
Objective: To analyze how governance and funding of primary care may impact the utilization of DHS for chronic diseases in Sweden.
Methods: Analysis of how models for funding, payment, policy and monitoring of quality of care may influence uptake of DHS.
Results: Funding, payment, and policy is not aligned with the ability to measure relevant outcomes of chronic diseases in primary care.
Conclusions: There is a need for holistic governance to optimize integrated care of chronic diseases with a mandate to ensure the utilization of the best interventions to improve the quality of care and reduce the cost. This also represents a pre-requisite for effective use of DHS.

Key words

Digital health, Chronic disease, Governance, Integrated care

1. Introduction

Lessons learnt:

- Funding mechanisms conflicts with the result of integrated care in primary care for chronic diseases
- The monitoring of results in integrated care does not provide an answer about the quality of care to inform a decision maker about the value for money.
- The case study of a diabetes monitoring device demonstrates the conflict between the funding mechanism and the aim to provide good diabetes care.
- The disconnect between funding and quality monitoring of integrated care in chronic diseases is a likely barrier in the uptake of digital health solutions

The increase in the burden of chronic diseases (CD) in the last 20 years represents a crucial concern (1), responsible for 86% of all deaths and accountable for 70-80% of all healthcare costs in the European Union(2). This increasing demand requires a shift toward primary care (1), creating new challenges in the organization of integrated care. This goes beyond providers in the healthcare system involving the self-management from the patient, developing skills of solving challenges related to their diseases(3). Self-management interventions have demonstrated statistically significant improvement in the outcomes of CD (4) and as such represent an important tool to address the challenge at hand. Integrated Digital Health Solutions (i-DHS) has the possibility to play an important role in the evolving integrated care for CD, centered around the patient and the primary care(5) (PC).

While there is much hope about the potential value of i-DHS, current utility is rather limited, leading to the discussion and analysis of how to overcome the challenges and barriers. The position paper from the European Society of Cardiology provides a summary of the barriers for adoption: stakeholder resistance and legal, ethical & technical barriers and the lack of reimbursement with the associated Health economic evaluations(6). Considering the potential for a DHS in chronic diseases a systematic review was carried out to understand the impact of implementation strategies, indication that there were several internal and external factors influencing the success of the implementation (7). Neither of these (6,7) consider the role of the overall governance as a potential factor influencing the implementation or as a potential barrier.

Aligning with the perspective of self-management intervention, a recent European evaluation found that Sweden was at the forefront of patient empowerment and ambition to implement integrated care and as such it represents an important example to evaluate funding and policy implications for chronic diseases from an international perspective (8). The Swedish government has declared the ambition to be the best in the world by 2025 in the utilization of digitalization and e-health to empower the population in achieving good health(9).

The governance and financing of healthcare in Sweden is governed autonomously by the 21 regions within the national legal framework, assisted by different agencies on a national level (10). Similar to many other countries, primary care has a central role in the management of chronic diseases, but in contrast to the funding to many other countries, the primary funding model is through capitation (11). Such population based capitation should provide incentives for integrated care with flexible approach to how the work is carried out (12) and as such provide a setting where DHS could be easily integrated. Despite these supportive circumstances, the uptake of DHS for chronic diseases is limited to less than 1000 patients(13) in the 3 large regions of Sweden representing more than half of the population. The limited uptake of i-DHS in CD(13) combined with the ambitious agenda to use digitalization(9) and the developed integrated care with primary care at the center, this suggests that there is need to analyze the role of governance and how it may influence the successful utility of i-DHS.

2. Description

2.1. Policy development – Impact of funding and governance in use of digital health

The funding of PC in Sweden is primarily based on a capitated budget based on the enrolled population, adjusted for factors such as age, sex, socioeconomic and prior disease history. There are additional schemes for how drugs, medical aids and diagnostic are funded, which vary across the regions in Sweden. These schemes can include separate additional full funding, partial or no additional funding. In

the later scenarios, there is a compensation incorporated in the overall capitation. When there is no additional funding there is a financial disincentive to use more expensive options. Whereas capitation is suggested to be the best option for population health (12), it requires a broader scope of responsibility in the case of the 4CD, where the benefit of good care results in a saving outside PC. With this limitation in the basic funding model, it is important to understand if there is relevant monitoring of outcomes in relation to the 4CD, either as a basis to initiate actions due to bad performance or to provide financial incentives for good results. If there would be such monitoring combined with measures to optimize good outcomes for the 4CD, it would in combination with a funding mainly based on capitation provide a context where it would be attractive to implement i-DHS. On the contrary, if there is an absence of appropriate measures to ensure outcomes of care, where the i-DHS leads to an increased cost for the PC, there would be limited interest to implement such solutions.

2.2. Responsible governance of health care – framework for analysis

With the aim to understand the potential impact of the regional governance of chronic diseases and the consequent impact on the utility of i-DHS, we have applied a framework for responsible governance (Figure 1). The framework illustrates the main areas of analysis to understand the need for improvement in terms of clinical and/or economical outcomes to guide the selection of appropriate intervention and thus enabling responsible governance. The analysis includes the three highlighted areas of the figure. For the scope of the analysis, we have included four chronic diseases (4CD): Chronic Obstructive Pulmonary Disease (COPD), Type two Diabetes Mellitus (T2DM), Hypertension (HTN) and Heart failure (HF).

To understand the value for the patient, we captured the current variables used by the regions to monitor the outcomes of 4CD. In the analysis, we are interested to understand and evaluate if they can provide a holistic result for the disease in question, Outcomes That Matter (OTM) (14).

To optimize the cost for the payer, different models for funding and reimbursement is deployed to optimize cost control and financial drivers to influence healthcare delivery (11). We have analyzed the basic funding model of primary care, monitoring of performance as well as the specific payment schemes for drugs, diagnostics, and Medical Aids (MA). MA is the existing category that would be applicable for DHS.

The use of national guidelines and recommendations has a central role to shape the policy of the health care delivery. To understand the impact of policy, we evaluated the change in utilization of Free Style Libre (FSL), a medical aid in diabetes monitoring, where a recent change in policy was introduced.

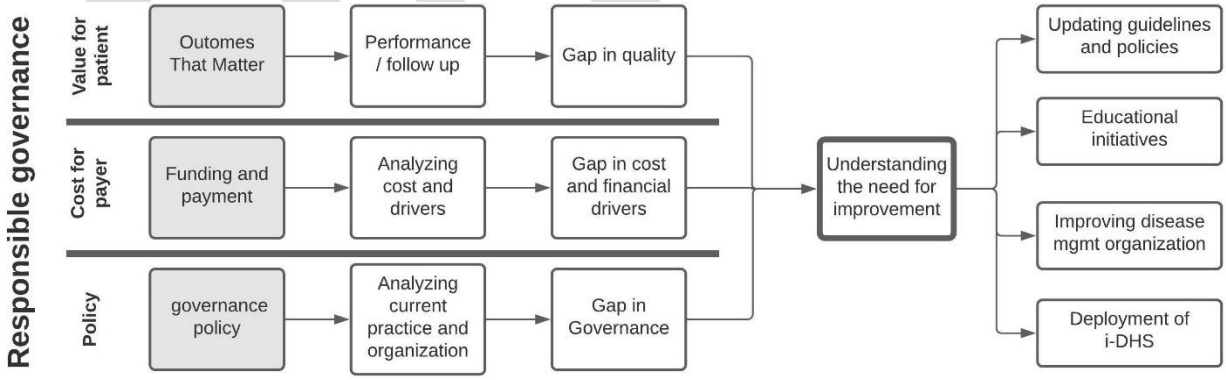

Figure 1 Responsible governance driving improvements.

2.3. Preventable hospitalizations

Suboptimal care of chronic diseases leads to unnecessary hospitalization, with a significant impact on the overall healthcare cost. The preventable hospitalization days per 100 000 has decreased during the three last reported periods (Graph 1), COPD 16.3 %, Diabetes 36,1% and Heart Failure 14.3%. In comparison

with the average of 21 European countries(15), Sweden has less hospitalization; COPD and Asthma 19.1%, Diabetes 39.7% and for Congestive Heart Failure 15.2%.

2.4. Data collection

To map the performance monitoring and funding in Swedish primary care, a search for the health care governance documents was undertaken for all the 21 regions in Sweden. The documents that govern primary healthcare provision and associated services were accessed from the website of each region and carefully reviewed focusing on key areas for this research: funding, disease indicators, diagnostics, and medical aids. If there was no clear answer in the public documents, correspondences were made with the different personnel of the Swedish regions to clarify outstanding issues.

We used a standardized template in share point as a data extraction tool for all the variables. For each of the data points, the reference to the original source is provided, when there was personal communication, it is summarized in a document on file per region.

To analyze the policy for FSL, we evaluated the national guidelines by the National Board of Health and Welfare (NBHW) and the evaluation by the Medical Product Council (MPC), comparing the anticipated use according to the indication with actual use.

2.5. Analysis of OTM, Funding and Payment

The extracted data was transferred to excel spread sheet for regional comparison analysis among the 21 regions, where a quantitative analysis of the variables was carried out.

2.6. Analysis of Policy

To analyze the impact of the policy change regarding FSL the utilization based on the statistical output “knappen” from the national diabetes registry was compared to the estimated population in the recommended indication.

3. Results

3.1. Value for patient

The methodological guidance (16) from NBHW for development of performance indicators is based on their role as an agency to provide evidence based national guidelines, to carry out assessments and to provide national comparisons. Recognizing the limitation in the scope of indicators developed by NBHW, they also outline the responsibility for the regions to develop indicators to ensure that they fulfil the legal requirement(17) to deliver good care. The NBHW guidance(16) outlines structural, process and result indicators (RI) where the latter is relating to a relevant outcome for the patient. The RI provides the best understanding of the ability to fulfil the legal requirement of good care, whereas the other indicators are indirect measures which may lead to good care.

In total there are 151 different indicators used in the monitoring across the regions (Table 1), where the T2DM has the broadest set of indicators (63) and most extensive utilization in the regions across the different categories of indicators. Most indicators are related to process related issues, which is helpful to understand adherence to guidelines but has very limited value to understand the outcome, such as illustrated by the examples. The regions with no monitoring indicators in relation to HF (76%) and HTN (67%) is high. For COPD and HF there are no indicators to evaluate results which is rather surprising considering the ability of primary care to influence the outcomes.

3.2. Funding and payment

The funding of primary care is dominated by capitation based on the number of patients assigned to the Primary Care Unit (PCU) representing 59-97.5% of the total budget. The regions use different models to adjust the capitation based on age (67%), Sex (10%), Adjusted Clinical Groups(18) (67%) as a method to describe the disease severity and Care Need Index (19) (95%) providing an index for social deprivation.

The remaining budget is mainly based on activity, complemented by a small portion related to activity, performance and to specific assignments. There is no performance payment linked to the 4CD. Based on the national initiative to shift the care out of the hospitals to primary care, there is a variable based on the ratio of visits within primary care relative to hospitals. This could influence the willingness to refer patients to specialists for additional investigations and thus be negative for chronic care integration. In most regions the primary care center is responsible for the cost of the drug they prescribe (76%) and similarly (81%) when they prescribe the use of a medical aid, which technically would be the existing category applicable for i-DHS, see (Table 2) for details.

3.3. Policy analysis

The use of FSL was included in the national guidelines by NBHW for T2DM published 2018(20) for patients with meal- or basal insulin in combination with reoccurring hyper- or hypoglycemic events. FSL has also been evaluated 2018(21) and 2020(22) by the MPC, representing the regions with the objective to evaluate and manage the introduction of new technologies. As part of this evaluation the Dental and Pharmaceutical Benefits Agency has carried out a health economic evaluation (23) indicating an annual cost per patient for the FSL of 1300 €, where the net difference compared to the use of traditional blood glucose monitoring, is estimated to be 550 €. In this evaluation (23) the target group is estimated to be 8000 patients based on the indication for T2DM. Data from the National Diabetes Registry shows that 1619 users of FSL year 2020 in T2DM represent 20.2% of target indication, an increase with 8,4% compared to previous year when there were 1494 users. Out of the users 2020, 24.4% is prescribed within primary care and the remaining within specialist care. In consideration, that this is a rather significant additional cost per patient in primary care whereas the saving will primarily come in secondary care. We investigated if any of the regions would provide any specific financial arrangement to reflect this. One (5%) region provided dedicated permanent funding for this medical aid within the defined indication, whereas other medical aids would be covered by the PCU (See table 2).

4. Discussion

The analysis demonstrates several important factors that individually represent potential barriers for the use of i-DHS, but more importantly it would suggest a gap in the governance to optimize the integrated care of the 4CD.

If there is an objective to accomplish a change in lifestyle, a question about lifestyle habits does not give any meaningful understanding of the result. A relevant indicator to evaluate the quality of care, would rather be how many patients where a lifestyle change is recommended have been able to accomplish a sustained lifestyle change. The result indicators for HbA1c and blood pressure give important value on a population level but do not have the same relevance in understanding the performance of an individual Primary Care Unit (PCU). For the individual PCU a ‘good result’ may rather be linked to the individuals assigned to the specific unit instead of the result of their work, hence this provides a description of the cohort than the outcome of the care.

Even though limitations in quality of care can be observed without data, the inability to capture relevant OTM’s in the monitoring of performance is an essential limitation for rational governance and choice of interventions to improve. Beyond the ability to make the right decision, it is an important limitation in the capability to monitor the effectiveness of the intervention. In a recent systematic review (24) and (25) an attempt has been made to standardize the monitoring of chronic diseases in primary care, however the purpose of why the monitoring should be carried out is not defined. In the Swedish context a national scheme has been developed to monitor primary care with the aim to support PCU’s in their internal improvement work, which does not necessarily correspond to the perspective of a decision maker. It is essential to capture relevant data for governance.

The financing of primary care does not provide any incentives to deliver good care of the 4CD, but on the contrary provide financial disincentives regarding the use of drugs, medical aids and diagnostics. As a primary care doctor pointed out during the project, should we prescribe the new effective diabetes drugs according to guidelines and consequently reduce our staff? While different payment models will impact different dynamics in the healthcare delivery, it is suggested that population based payment (PBP), such

as most dominant in the Swedish primary care, is the most favorable for preventive care(12). The value of the PBP is conditioned on the ability to incorporate the relevant long-term consequences of interest within the scope of responsibility. This is not the case for the 4CD in Swedish primary care, where the savings mainly come in hospital care whereas the effort to improve mainly will come from the PCU. When the PCU is also responsible for the cost of drugs, medical aids and diagnostics it creates additional barriers to optimize the preventive management of chronic diseases.

In an evaluation of governance models of effective drug-usage, several aspects were evaluated (26), but none relating to the outcomes. Payment for performance (P4P) in PCU has demonstrated effective in several studies in relation to process parameters such as registering data (27), adherence of drug prescription to guidelines (28) or appropriate use of antibiotics (29), all representing limited complexity and none with a link to result outcomes. Whereas the use of P4P to incentivize integrated care for frail older people demonstrate the complexity deploy such approach either for funding or accountability(30).

From the analysis, it appears that the payment schemes influencing the outcomes in chronic diseases, such as for PCU, drugs, medical aids, use of diagnostics and referral to specialists have been designed with a narrow focus to optimize the cost for the specific category. While current design of the programs optimizes the cost for each category, it also clear that it creates an important barrier to optimize the integration of care efforts. This is particularly important for the 4CD, where the PCU has a significant role to improve the long-term outcomes, leading to avoidance of healthcare interventions in secondary care with corresponding savings. While the regions are responsible to deliver effective care of high quality, it is not possible to find any attempts for a holistic governance of the 4CD to reduce the cost and improve the outcomes. The NBHW provides guidance and policy for the 4CD based on available evidence, however this only represent a fraction of guidance required to cover and to understand good and effective care. In the intersection between the national theoretical and the regional operational governance, there is a gap. We would suggest that there is a need for a role to actively work with management of the CD to optimize the integrated care and thus improve the quality of care and reduce the overall cost. The case study with FSL demonstrates that even though there is national policy and guidance supporting the use, there is very limited adoption of the payment schemes to support this. It is plausible that this is an important factor in the limited utilization of this technology, despite policy endorsement.

We would suggest that the lack of holistic governance and the ability to understand the relevance of the i-DHS to address the needs to improve, are significant contributors to the limited uptake of i-DHS.

5. Conclusion

The need to improve the integrated care for the 4CD is imminent and requires skilled leadership who can understand the need to improve, prioritize and select the appropriate interventions. The complexity of the issues requires relevant data to understand the problem and ability to evaluate the effectiveness of the selected interventions.
While considering the ability to make rational decisions about the utilization of i-DHS for 4CD in primary care in Sweden, we have found that there are important misalignments of financial drivers to provide good quality of care due to fragmented payment models and lack of holistic governance.

Each model for funding and payment has limitations in the ability to create the desired the dynamics and require skillful leadership to optimize the use of existing models. Making the PCU responsible for the cost of drugs, medical aids and diagnostics is effective to reduce cost. However, there are scenarios where a specific measure needs to be taken to address drivers that are clearly prohibitive for the quality of care such as illustrated in the case study where one region covers the cost for the FSL.

There is a need for holistic governance to optimize integrated care of chronic diseases with a mandate to ensure the utilization of the best interventions to improve the quality of care and reduce the cost. This also represents a pre-requisite for effective use of i-DHS.

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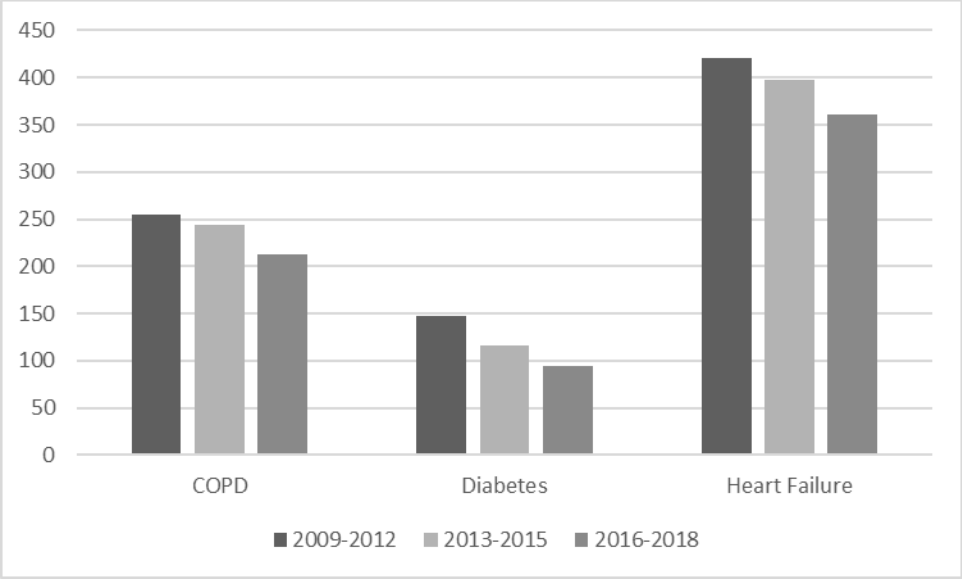
Table 1 - Number of indicators and proportion of regions utilizing category of indicators

Indicators		Examples	COPD	HF	HTN	T2DM
Number of variants			48	16	24	63
Structural		-	-	-	-	1
Process	Diagnostic:	Number of patients who carried out a spirometry	11	-	-	6
	Drug:	Percentage treated with statins	-	4	-	2
	Lifestyle:	Has the patient been asked about lifestyle habits?	7	-	3	6
	Registration:	Is the registration of data complete? Is there data about blood pressure for a HTN patient?	3	-	1	13
	Visits:	Has there been an annual follow up visit?	4	3	-	3
	Other:	-	6	4	5	7
Result	Blood pressure	Proportion of patient above, below or within a range.	-	-	4	8
	HbA1c:		-	-	-	14
	Other	-	-	-	-	2
No use of indicators			38%	76%	67%	10%

Table 2 - Funding and payment

Funding and payment	Category	Proportion
Funding by capitation	>90%	24%
	80-90%	48%
	70-79%	10%
	<70%	19%
Adjustment factors	Age	67%
	Sex	10%
	ACG	67%
	CNI	95%
Use of performance compensation	All	57%
	4CD	0%
Payer of drugs*	PC	76%
	Region	24%
Payer of diagnostics*	PC	86%
	Region	0%
	Data was not available	14%
Payer of medical aids*	PC	76%
	Region	10%
	Data was not available	14%
Special payment solution for the use of FSL in PCU	Covered by the region	24%

*There are minor differences in how the cost responsibility for the different categories is defined. The most dominant perspective has been selected.



Graph 1 - Preventable hospital days / 100 000