Mikko Nenonen and Olli Nylander

A Theoretical Framework
for Health Information Systems
Mikko Nenonen and Olli Nylander

A Theoretical Framework for Health Information Systems

Themes 3/2001

National Research and Development Centre for Welfare and Health (STAKES)
Helsinki, Finland
“For in much wisdom is much grief:
and he that increaseth data increaseth sorrow.”
“Eo quod in multa sapientia multa sit indignatio
et qui addit data addat et laborem.”

THE HOLY BIBLE Authorized Translation
& Versio Vulgata; Ecclesiastes 1:18 as presented by
Niiniluoto 1996(1) as a new
translation for the information society.
Contents

Introduction ........................................................................................................................... 4

‘Topographic map’ of Health Information System ................................................................. 4

The organisational levels of using data .............................................................................. 6

The knowledge hierarchy ..................................................................................................... 7

Metadata theories .............................................................................................................. 7

Organisation management theories ..................................................................................... 8

Synthesis of knowledge hierarchy and metadata theories .................................................... 8

Synthesis of knowledge hierarchy and organisation management theories ....................... 10
  Scientific management – Trait theory – Steering with resource allocation – Data .......... 10
  Administrative school – Leadership action-behaviour approach – Steering with norms – Information ................................................................. 10
  Bureaucratic school – The contingency approach – Steering with norms – Knowledge ................................................................. 11
  Human relations – Transformational leadership – Steering with information – Wisdom ................................................................. 11
  Other models .................................................................................................................. 11

Linking theories to a health information system model ..................................................... 11
  Step 1 ............................................................................................................................. 12
  Step 2 ............................................................................................................................. 12
  Step 3 ............................................................................................................................. 12

References .......................................................................................................................... 13
Health information systems (HISs) have been created by many countries and international organisations during the last ten years. Our personal experiences with these attempts have made us think that it cannot always be taken as guaranteed that even innovative approaches will lead to satisfactory results. The problem seems to be linked to the wish to create a comprehensive system containing many elements. On the other hand, several times also very simple measures that started with collecting data and refining them into indicators have produced only confusion when these indicators have been utilised in health care planning and administration both at local and national levels.

Finland faces the task of constructing an HIS. During the last 30 years we have already created some parts of the system, but a comprehensive system is still missing. Besides taking a practical and pragmatic approach, we have also tried to clarify the theoretical background, the framework of for such a system.

This paper presents the results of this conceptual and sometimes also philosophical work. It is based on a paper presented (MN) and accepted as ‘homework’ for ‘Management i nordisk hälsa och sjukvård’ course at the Nordic School of Public Health, Gothenburg, Sweden. Formulating this paper has taken us three to four years. It has acquired elements and ideas from numerous discussions with several Finnish experts, and also from international organisations like WHO, OECD and Eurostat. The preliminary versions of these ideas have been presented at several congresses: e.g. IAOS (Aquascalientes, Mexico), ISI (Helsinki), WONCA (Tampere). This framework has also been utilised in the evaluation process for the ‘Makropilotti’ project. We want to thank all those who have found time to discuss these ideas with us and have thus helped us to further develop these ideas.
Introduction

As an HIS has many components, so does its theoretical framework. This paper starts with more concrete issues like the ‘topographic map’ of the system and possible organisational levels for using the data. It proceeds then to the concept of knowledge hierarchy and to metadata theories. Finally it links all these together with organisation management theories.

'Topographic map' of Health Information System

We divide HIS into two major parts: a clinical part and an administrative/statistical part. The difference between these two is the way the data are used. In clinical work they are linked to a real patient either via a name or a unique personal identifier. Decisions concerning this patient are made based on this information; thus there is a high demand for data accuracy and correctness. In the administrative/statistical part of the system, data are separated from the patient and are no more used in decision-making concerning individual patients. Thus the demand for absolute correctness in each individual case is not so high. Instead the usefulness of the data at this level is highly dependent on definitions, comparable use of codes etc. The data from an administrative/statistical system may not in any case be traced back to the patient again. This principle is also the key to the data security of an HIS.

The clinical part of an HIS is composed of two elements (Figure 1):
- The clinical databases that keep the clinical data in order and always linked with the correct patient.
- An evidence-based decision support and expertise system that provides the clinician with the latest critically reviewed scientific information.

The administrative/statistical part of the system has three elements (Figure 1):
- A business reporting system that provides information on the production and on the use of services for benchmarking purposes and also for management at local, regional and national levels. This has traditionally been called as ‘health care statistics’.
- An epidemiological information system that contains information on the incidence and prevalence etc. of diseases or health conditions, living habits, and health hazards and that also serves the purposes of disease surveillance and early warning mechanism.
- A quality system that ensures the high quality of services provided to the population.
These five main elements are composed of many subsystems and they are also linked together in a complex manner (Figure 2). The basis of feeding information to these subsystems are the clinical databases. The data collected are created in doctor’s or nurse’s offices, hospitals etc. They are stored in these databases and used in clinical work. Together with this clinical information some administrative data are also collected for local use. This data together with coded (e.g. ICD-10, ICPC, ICIDH2 etc.) clinical data are relayed to the administrative/statistical systems. Data collection for only administrative/statistical purposes should be avoided as much as possible.

The business reporting systems or national health statistics have traditionally been based on causes of death statistics. More and more countries have built either register- or survey-based systems for hospital discharge statistics. These have been widened to include outpatient care as the focus of health care has moved away from institutional settings. The latest development in business reporting has been the interest in the economic side of health care (2). This calls for the inclusion of data on health care personnel and equipment.

In some countries also other elements are included in the national HIS. In the Irish plans for their new system one such element is the consumer/patient information module. This combines elements of business reporting and decision/knowledge support in simplified form to be understood by the layman. This system may also include local information like addresses of clinics, availability of services etc.
The organisational levels of using data

In modern HISs the use of the data starts already at the doctor’s office. Besides in clinical work health professionals are more and more using the data in their clinical databases to evaluate the effectiveness, costs, productivity and comprehensiveness of their work. This becomes especially important if the professional has so-called population responsibility for his or her patients. This demands active follow up of chronic diseases, use of epidemiological background data etc.

At local level the focus is on effective and economic provision and production of services. The data are still linked to individual patients and used e.g. for identifying and streamlining the services used by ‘expensive patients’ or patient groups. More and more administrative data are, however, used for, e.g. benchmarking purposes (benchmarking doctors and benchmarking municipalities and clinics). At regional level the use is mainly administrative and for example in Finland the data cannot legally deal with individual patients. Here the focus is on service networks and introducing the ideology of seamless care. At national level the demands for equity, effectiveness, safety and quality together with the formulation of the national health policy set high demands for the information system. In future the role of international organisations is going to increase. For instance the European Union is now taking an increasing number of actions and roles which earlier were discussed only in the context of individual nations.

Figure 2. The subsystems of the five main components of an HIS and their interactions and relationships. The borderline between the clinical (bottom) and administrative/statistical systems (upper) is depicted as a black line. Patient-level information passes this border only in one direction.
The knowledge hierarchy

Many languages have problems with words like data and knowledge. For instance, the Finnish language uses only one word *tieto* for three different concepts: data, information and knowledge (1, 3). However, even in languages with less confusing words, there is a lot of space for misuse and misunderstanding of these words (3). In his review Tuomi (3) discusses several theories and models for data hierarchy and presents also what he calls the ‘conventional view on the knowledge hierarchy’: data – information – knowledge – intelligence – wisdom. Tuomi also heavily criticises this hierarchy, because in his work he starts with corporate knowledge and tries to implement it at the level of data: For HIS needs the levels data – information – knowledge – wisdom seem to be sufficient to describe the system. We start with data and refine it first into information and then into knowledge. Thus the hierarchy may be seen both bottom–up and top–down. A conclusion from Tuomi’s studies might be expressed as follows: people communicate at the level of knowledge and information, computers communicate only at the data level. They also store only data, not information and wisdom.

Metadata theories

In statistical work the limited nature of data and information in providing elements for decision-making has been recognised for decades. To compensate for this limitation, different systems that provide background information necessary to understand the data or information have been constructed. These systems contain usually information about the method of data collection, definitions of variables, completeness of data etc. These information has been called ‘metadata’, data on data. This concept has, however, also been corrupted with similar confusing meanings in the same way as the concept of ‘knowledge’. For some persons metadata has meant only information directly linked with the actual data elements, and to others it has included the understanding of the operation of the national health care system. Sundgren (4) tries to structure this concept by dividing it into two elements which he calls local metadata – linked directly with data, and global metadata – giving more common background information.
A Theoretical Framework for Health Information Systems

Organisation management theories

Contrary to the relatively little discussed and few metadata theories, organisations and management have produced a wide collection of different theoretical approaches. In their book ‘Integrerad organisationslära’ Bruzelius and Skärvad (5) present the four classical organisational theories: *scientific management* (Frederick W. Taylor), *the administrative school* (Henri Fayol), *the bureaucratic school* (Max Weber) and *human relations* (Elton Mayo).

In building a theoretical framework for HISs these theories could be used together with four theories on leadership presented by Jreisat (6). *Trait theory* (1940–1950) focuses on the personal characteristics of a person born to be a leader. The *leadership action-behaviour* approach is interested in the way the leader behaves. It identifies three styles: authoritarian, democratic and ‘laissez-faire’. The *contingency approach* observes how the leader reacts in different situations, and *transformational leadership* tries to motivate, delegate, inspire and create innovative culture for the organisation.

In health care at the national level the term ‘management’ is not generally used. Instead we speak about *steering with norms*, *steering with resource allocation* and *steering with information* (Huttunen, J., personal communication 2001).

Synthesis of knowledge hierarchy and metadata theories

In order to facilitate the structured production of statistical information in social welfare and health care, we have developed a synthesis of knowledge hierarchy and of the metadata theories presented above (7). Figure 3 gives a schematic presentation of this relationship. *Data* is here understood as simple data elements like one record of discharge data with a diagnosis, derived from patient databases. When these data are linked together with definitions of data items, ICD-10 codes etc., it is possible to create *information*, like the average length of stay in a certain diagnostic group. Thus information and indicator are near synonyms in this respect.

When information, such as average length of stay, is linked with relevant background information, such as knowing the local service structure and national clinical guidelines, it will be possible to create *knowledge*, i.e. understanding of how these patients are treated in that region. When this knowledge again is linked with relevant background information, like the personal experience of the responsible civil servant or physician, understanding of the operation of health care system as a whole,
international experiences, theories, ideas etc., it may be possible to gain wisdom, true understanding of this phenomena. This wisdom may even facilitate visionary work, creating new and better ways of solving some problems in the old system.

In this model the four levels of knowledge hierarchy are thus linked with the two levels of metadata presented by Sundgren (4). Local metadata here equals the lowest meta level, ‘metadata’. Global metadata is divided into two elements for the remaining levels of knowledge hierarchy: ‘metainformation’ and ‘metaknowledge’. We could also speak about ‘metawisdom’, but because the amount of transferable and communicable objective elements decreases when one goes higher in this hierarchy and the meta-element also becomes more subjective, not transferable to other persons, this term is not used.

This model also explains why we cannot solve problems linked with sharing knowledge only by promoting the free exchange of data: We omit the meta-elements and the information level of the hierarchy. There is at present only limited experimental evidence supporting these hypotheses. One of the few existing studies tested the effects of sharing data between a laboratory and an emergency department by computer system instead of using telephone to communicate lab test results. When used as the sole means for transmitting results, the provision of terminal access to laboratory results on wards hindered rather than promoted the communication of emergency blood results to health care staff (8).

Figure 3. The relationship between the knowledge hierarchy and metadata creates a cascade starting from data and creating wisdom when data elements are linked with corresponding background information (metadata). Modified from (7)
The model also shows how visionary work needs data, information and knowledge as building blocks, but cannot be based solely on these elements. Only when these elements are linked together with corresponding meta-elements to create wisdom will visions also have a solid basis.

One special element of these meta-levels are different classifications and definitions. On one end of these classifications are ‘clearly’ defined clinical classifications like ICD-10 and procedure classifications. These are often used at the most objective level, the data level, to classify and describe the basic registered events. When classifications and definitions are used on higher levels, like on the knowledge or wisdom level, they become more subjective and also culture-sensitive.

**Synthesis of knowledge hierarchy and organisation management theories**

Different types of management and leadership have different needs for data, information, knowledge and wisdom. Here we present some identifiable, although highly simplified and hypothetical models.

**Scientific management – Trait theory – Steering with resource allocation – Data**

Scientific management relies heavily on data. The processes and actions of the inborn leader are guided (besides by subconscious intuition) by data, often without relevant background information. The approach is very mechanistic. Nowadays systems based on free movement of data between organisations represent a way of returning back to this ‘scientific’, reflex-like management system. Also in health care systems, steering based on resource allocation is more or less mechanical. The Finnish Ministry of Social Affairs and Health published at the beginning of 2001 a strategy and health policy paper mentioning the concept **steering with supervision or control** (9). We would place this form of steering under this heading as well because it is based on the use of data and indicators, and produces more or less mechanical reactions to things which have already happened.

**Administrative school - Leadership action-behaviour approach – Steering with norms – Information**

These systems are guided by indicators, i.e. information. Often one finds certain ideal ranges and alarming values, which release different actions. This kind of system is relevant when rapid and structured actions are needed in potentially dangerous situations. In health care systems, the central administration uses information to supervise health care organisations and professionals.
Bureaucratic school - The contingency approach – Steering with norms – Knowledge

Here the reactions of the organisation and its leader/manager vary and there is a clear knowledge-based element. One still finds strong systems of information/indicators and also actual data in these organisations. Personally we would place also ‘balanced scorecard’ systems in this category. The health care system uses indicators to react to the population’s needs and, e.g. underproduction or overproduction of services.

Human relations - Transformational leadership – Steering with information – Wisdom

This is seen as the most demanding but also the most productive system of managing an organisation. It is often seen in IT companies when the value of their shares rockets high. A fall in shareholder value normally causes a return to more data-intensive and rigid models. For health care systems this is also the most demanding mode of leadership or steering. Here the health care organisations, service providers and professionals should become active users of data and information and create their own knowledge, wisdom and visions in line with the national guidelines set in health policy.

Other models

There is still at least one further type of health care management and leadership. This type does not generally base its actions on data or information; instead it relies on intuition, political programs, devotion etc. For this type of management data and indicators are often even seen as disturbing factors, and the data will be adjusted to the needs presented on higher levels of data hierarchy, often on the visionary level. In this model the metalevels are kept as lean as possible to avoid transparency of data and indicators. This model is in other settings sometimes called ‘flying by (the seat of) your pants’.

Linking theories to a health information system model

The use of these theories makes it possible to crystallise the process of building an HIS into three steps. This is naturally a very schematic presentation and no one should start to build an HIS using only these few lines as a guide. We see merely these steps as an end-result of a long process of reading, thinking and discussing with colleagues, and national and international experts.
Step 1.

The process of building an HIS starts with identifying one’s location on the ‘topographic map’. We must be aware of the location of the element we are planning to build. A business reporting system for in-patient care cannot fulfil epidemiological data needs on type II diabetes and a system for outpatient statistics cannot serve as an early warning system for product hazards. Also the potential data sources, data security aspects and systems benefiting from the use of the same data should be identified.

Step 2.

In order to define the data content and its level of detail we should use a knowledge hierarchy vs. level of using the data matrix to be able to identify what is actually needed on each level. For different types of health conditions there are different information needs: e.g. for visits to the doctor because of common cold the total number is often enough. For diabetes it is the content of whole service episode including outpatient and inpatient care, use of laboratory resources etc. The matrix is presented in Table 1. The level of detail is highest in clinical work. On higher levels the information content becomes more and more structured and coded and simultaneously the role of metalevels increases.

Table 1. The ‘knowledge hierarchy’ vs. ‘level of using the data’ matrix. Different health conditions will require different levels of detail in knowledge, as well as different levels of information at the various levels of organisation (clinical through international)

<table>
<thead>
<tr>
<th>Data</th>
<th>Information</th>
<th>Knowledge</th>
<th>Wisdom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population responsibility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regional level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>International level</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Step 3.

The health care steering and administration system should be identified and the data needs adjusted to national health policy. This cannot be the first step, because this approach would lead to a jungle of details and unstructured wishes to ‘know everything’ and to have ‘all the data’. The matrix from step 2 also helps to put into perspective the data needs for steering the health care system.
References


Health information systems (HISs) have been created by many countries and international organisations during the last ten years. Our personal experiences with these attempts have made us think that it cannot always be taken as guaranteed that even innovative approaches will lead to satisfactory results. The problem seems to be linked to the wish to create a comprehensive system containing many elements. On the other hand, several times also very simple measures that started with collecting data and refining them into indicators have produced only confusion when these indicators have been utilised in health care planning and administration both at local and national levels.

Finland faces the task of constructing an HIS. During the last 30 years we have already created some parts of the system, but a comprehensive system is still missing. Besides taking a practical and pragmatic approach, we have also tried to clarify the theoretical background, the framework of for such a system.

This paper presents the results of this conceptual and sometimes also philosophical work. It is based on a paper presented (MN) and accepted as ‘homework’ for ‘Management i nordisk hälsa och sjukvård’ course at the Nordic School of Public Health, Gothenburg, Sweden.