Information requisition is the core of guideline-based medical care: which information is needed for whom?

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Abstract

Rationale, aims and objectives It is mandatory for the design of an efficient software product to know the different groups of users of a software tool, the tasks the users want to perform with it, and the information that is required for it. Our goal is to establish a comprehensive information source for the development of a consistent software environment supporting all tasks emerging from the creation to the execution of a computerized clinical practice guideline (CPG) for different user groups.

Methods We conducted a comprehensive literature review to investigate the different user groups of a computerized CPG as well as their specific information needs.

Results We provide a complete catalogue of every single aspect that may be related to information needs of any party concerned. In particular, we give detailed information on the tasks of guideline modellers on the one hand, and clinical information needs (i.e. information needs of physicians, nurses, nurse practitioners and patients) on the other hand.

Conclusion By providing categorized information from several studies and publications, we establish an exhaustive information basis for the design of a useful software tool facilitating the formalization and the execution of a CPG.

1. Introduction

Clinical practice guidelines (CPGs) [1] are powerful tools to improve the quality of health care [2,3]. However, existing guideline formalization approaches [4–6] point out important benefits of a consistent software environment supporting all tasks emerging from the creation of a computer-executable model of a CPG to its actual implementation in clinical care (e.g. translating the medical knowledge of a textual CPG into a computer-interpretable model, applying a recommended therapy on a patient, or answering clinical questions). Among others, these benefits are [4–6]:
• providing links between the different models of the guideline, that is the textual guideline, the intermediate representations in the modelling process, and the computer interpretable model;
• backtracking given recommendations to their source in the original text and vice versa, if any parts of the guideline text are to be changed; and finally
• facilitating maintenance and modification of the guideline by applying corrections and changes in one model to all the other models as well.

Hence, a guideline software system has to be designed to deal with all given tasks and different user groups (knowledge engineers, physicians, and so on). Unfortunately, there is a lack of comprehensive information on (1) the different user groups of such a tool; (2) what tasks a user wants to perform with the software product; and (3) what information is required for it. This information is mandatory to make valid decisions on the design of a software product [7].

This paper therefore deals with a presentation and analysis of a number of representative research studies carried out in related fields – namely the formalization of a clinical practice guideline, information needs arising in clinical care, as well as information needs of patients – in order to establish a sound basis to meet the challenge of designing a software system supporting both the modelling process and the application of a CPG.

To start with, we present an outline of our approach as to the review of literature in Section 2. In Section 3 we describe the findings of the literature review; in particular, we describe the information needs of guideline modellers in Section 3.1, where we differentiate between the tasks involved in modelling a CPG.
in a model-centric way (Section 3.1.1) and those of a document-
centric approach (Section 3.1.2). We continue with a detailed
description of the information needs that arise in clinical care in
Section 3.2. We have investigated the information need of physi-
cians (Section 3.2.1), nurses and nurse practitioners (Section
3.2.2), and patients (Section 3.2.3) separately. Finally, we discuss
the main results of our work in Section 4.

2. Methods
We conducted a comprehensive literature review to investigate
the information needs of different user groups of a computerized
CPG. As a first step, we have examined the available literature to
derive which user groups are actually involved in the development
cycle of a CPG. Subsequently, we have focused our review on the
different tasks involved in the modelling process of a clinical
practice guideline as well as on the information needs of caregivers
and patients.

We have examined several Internet resources for relevant
scientific papers. On the one hand, we have looked for papers
of specialized organizations and journals focusing on medicine
e.g. PubMed [8], Medical Library Association [9], British
Medical Journal [10]) and others focusing on medical informatics
e.g. American Medical Informatics Association [11], Artificial
Intelligence in Medicine [12]). On the other hand, we have used
general search engines (e.g. Google Scholar [13]) looking for
scientific papers matching terms such as ‘clinical practice guide-
line’, ‘nurse information needs’, ‘clinical information needs’, etc.
In addition, we have checked the reference lists of relevant articles
for additional information.

3. Results
In a first step we have derived different user groups involved in the
development of a computer-executable CPG or in the application
of a CPG in clinical care [14,15]. Moreover, involving patients
in decision making has shown to improve the effectiveness of care,
to increase the efficiency with which the treatment is delivered,
and to lead to a better acceptance as well as to improved outcomes
[16–18]. This led us to focus on these four different user groups:
• guideline modellers,
• physicians,
• nurses and nurse practitioners, and
• patients.

In the following subsections a detailed outline of tasks and
information needs of the different user groups is given.

3.1. Formalization of a CPG
The main task of a guideline modeller – no matter which model-
ing approach – is to create a formal guideline representation
model of the original narrative guideline. To support a modellers
task of creating a formal model, he/she needs to know (1) of which
components the target representation format is composed and (2)
in which way scheduling constraints are to be modelled [19,20]:
(1) Components: the investigated guideline representation
models are composed of plans (sometimes also called guidelines,
templates or maps). A plan can be decomposed into:
• Actions: the modelling primitives that represent the
actual tasks described by clinical guidelines (e.g. medication
prescriptions and clinical investigations).
• Decisions: the investigated guideline representation lan-
guages use different decision models to formalize the deci-
sions intrinsic to the recommendations of a clinical guideline
(for a detailed comparison see [20]).
• States: a plan component that defines specific scenarios, that
is patient states and execution states. Patient states are char-
acterized by a patient’s condition (e.g. hypertension) and are
often used to facilitate the automatic entry into appropriate
guidelines. Execution states are characterized by the current
condition of a specific plan (e.g. started, completed).
• Sub-plans: usually guideline plans can be decomposed into
sub-plans (also called sub-guideline, task, protocol or com-
posite action), which in turn may consist of various sub-plans.
The nesting of plans and sub-plans leads to a hierarchical
structure of guideline plans.
• Branch and synchronization steps: are used to model parallel
treatment options in the guideline. In some cases, parallel
and sequential plan executions are modelled without branch
and synchronization steps (e.g. by plan characteristics).
(2) Scheduling constraints: guidelines may involve sequential,
parallel, iterative and concurrent care processes. Most guideline
models use flowchart-like representations to define the execution
order of plans, that is, sequential, parallel and cyclical execution.
Other models use more precise scheduling constraints or complex
time annotations to manage the task execution. Decision models
are also used to govern aspects of control flow.

There are two basic types of formalization: a model-centric
approach and a document-centric approach.

3.1.1. Model-centric formalization
For model-centric formalization a medical domain expert for-
mulates a conceptual model of a guideline, based on the original
narrative document but without a direct relationship between the
original text and the model. There are diverse guideline represent-
ation languages as well as tools to facilitate the translation process
(for a detailed comparison we refer to [19,20]). However, only few
descriptions allow the derivation of how to model a CPG in detail
[21,22]:
1 Identification of relevant guideline knowledge: medical experts
with informatics training need to analyse the desired guideline
recommendations and determine the knowledge and logic needed
to generate these recommendations.
2 Disambiguation of guideline knowledge: for instance, the term
‘contraindication to Hep B’ is disambiguated by the definition
‘anaphylactic reaction to hepatitis B vaccine’.
3 Identification of clinical concepts, fundamental parameters
and their interrelationships: clinical concepts and other funda-
mental parameters are to be identified, extracted and recorded
(e.g. ‘hepatitis B vaccine’ and ‘anaphylactic reaction’). Moreover,
interrelationships have to be defined.
4 Generation of detailed data models of the previously identified
concepts and parameters: the previously identified concepts are
instantiated as detailed data models. For instance, allergy informa-
tion is modelled as an instance of the class Allergy, which has the
attributes code, allergen, reaction and effective time. Hence,
‘Anaphylactic reaction to hepatitis B vaccine’ is modelled as
Allergy where ‘vaccines allergy’ is assigned to the code attrib-
ute, allergen is defined as ‘hepatitis B vaccine’ and reaction is
‘anaphylaxis’.
5 Generation of a mapping of the terms in the knowledge base
to the terms of the specific institution: creation of a standard
vocabulary.
6 Specification of a logical and process structure of the guideline:
generating a flowchart-like model of the guideline knowledge
corresponding with the recommendations.
7 Encoding the model in the specific XML format.

However, literature provides more detailed descriptions on how to
model clinical guidelines in a document-centric way.

3.1.2. Document-centric formalization

We have investigated various approaches [6,23–26] to formalize
a clinical practice guideline in a document-centric way. These
approaches use different (and not always coherent) methods to
do so. Some formalization steps are part of each of the different
modelling approaches, for instance, the marking up of relevant
parts of the guideline text; others are only mentioned once, for
instance, replacing passive voice by active voice. This does not
necessarily mean that these steps are not part of other approaches,
too, but they are not explicitly mentioned in the description of
these approaches. In order to arrive at a comprehensive represen-
tation of the formalization process, we have categorized and
listed all the steps mentioned. Based on the various findings of
the literature review, we have generated an algorithmic repre-
sentation giving a complete overview of every conceivable detail
that might be considered important in transforming a textual CPG
into a guideline representation model using a document-centric
approach (see Fig. 1). This list serves as a checklist to improve
existing methods and, even more importantly, as a comprehensive
reference to decide about required functionality of a software tool
to support the document-centric formalization process.

3.2. Clinical information needs

The preceding section of this paper (Section 3.1) deals with tech-
nical aspects of the guideline modelling process; the following
deal with user expectations and requirements that have to be con-
sidered in creating a clinically useful software environment. An
outline of categorized findings of clinical information needs
derived from diverse studies is given in Figs 2–11.

3.2.1. Physicians’ information needs

It is to be expected that physicians will be the ones who will most
frequently work with such a tool. As regards the information
sought by physicians, a number of studies have been conducted,
mainly in the form of retrospective questionnaires, interviews,
self-reports and observation [27–36].

Because of a lack of data and the heterogeneous categorizations
of information of the different studies, the frequency of informa-
tion categories can only be a rough estimate. Thus, a tentative
conclusion is offered instead; the information categories are listed
according to their priorities:

1 Information about treatment (e.g. recommended treatment, spe-
cific procedures, effects and side effects); of particular importance
is information on medication (e.g. recommended medication,
effects and side effects, efficiency).
2 Information relevant for diagnosis (e.g. possible causes of
symptoms, relations between findings, indicated tests).
3 Information on patient data (e.g. symptoms, medical history,
test results).
4 Information about other health care providers (e.g. contact data
of colleagues and other specialties).
5 Information about a specific disease (e.g. prognosis, aetiology).
The majority of questions posed by physicians deal with therapy
and especially with all sorts of aspects associated with medication.
The physicians’ main interest seems to be the correct drug, its
effectiveness, its side effects, dosage and how long it should be
taken. Diagnostic questions also appear quite frequently, but ques-
tions concerning the prognosis, the aetiology of disease and so on
seem to be of comparatively little concern, if we are to believe the
findings in Figs 2–11.

3.2.2. Nurses’ information needs

When focusing on the information needs of nursing staff
[34,35,37–41], it is interesting to note that there is little difference
between the questions posed by nurses and what the physicians
want to know (see Figs 2–11). The only real difference seems to be
their respective focus of attention: for instance, the nurse-patient
relationship being of a more personal nature is reflected by the
nurses’ interest in psycho-social support of patients whereas
physicians have not formulated such questions in the studies
investigated in this paper.

As nurses and nurse practitioners’ differ in competence, we list
their categories of major interest separately. These are for nurses
(sorted according to their priority):
1 Information about treatment; of particular importance is infor-
mation about institution specific procedures and information on
medication,
2 Information on patient data (e.g. findings, test results, allergies).
3 Educational material and information on instructions for the
patient.
4 Information about a specific disease (e.g. description, symp-
toms, risk factors).
5 Information about other health care providers (e.g. contact data,
when to seek advice, information about specialties).
6 Information relevant for diagnosis (e.g. possible causes of
findings, calculation of findings).

On the other hand, nurse practitioners require:
1 Information about treatment; of particular importance are
information on medication.
2 Information relevant for diagnosis (e.g. indicated test, differen-
tial diagnoses, relations between findings).
3 Information on patient data (e.g. findings, test results, allergies).
4 Information about a specific disease (e.g. aetiology, epidemiol-
ogy, prognosis).
5 Information about other health care providers (e.g. contact data,
when to refer patients, information about specialties).
6 Information on psycho-social support for patients.
7 Educational material and information on instructions for the
patient.
Figure 1 Tasks of document-centric guideline formalization.
These lists show the different priorities of nurses and nurse practitioners. The main difference is that nurse practitioners are more concerned with diagnostic issues than nurses. In accordance with the results for physicians, nurses and nurse practitioners need most information about treatment and diagnosis, in which they require information about institution specific procedures and medication quite frequently. In contrast to the results for physicians, there is an obvious need for information on psycho-social support for patients.

3.2.3. Patients’ information needs

The information desired by patients [42–51] is more voluminous than either the questions formulated by physicians or those formulated by nurses, as they are not only worried about illness itself but also about the effects this illness has on family members, precise information on circumstances they are likely to expect when visiting other medical facilities and, last but not least, detailed information about available psycho-social support.

The most important categories of information for patients are (sorted according to priority):

1. Information about treatment (e.g. therapeutic options, risks and benefits, therapeutic procedures); of particular importance is information on effects of the treatment (e.g. on quality of life, physical and emotional effects).

2. Information about their disease; of particular importance are information on individual prognosis, chances of recovery and information on their diagnostic stage.
3 Information on available psycho-social support (e.g. other people's experiences, mental health workers, voluntary organizations).

4 Information regarding their family (e.g. risks for family members and how to handle physical and emotional impact on family members).

5 Their patient data (e.g. test findings).

6 Prevention of specific disease or recurrent illness.

7 Educational material and instructions (e.g. information on treatment and disease, diet, exertion, pain relief, preparation for treatment).

It is evident from our results that patients' information needs differ qualitatively from physicians' and nurses' information needs. They
require much more detailed information on emotional effects of their treatment and its effects on their quality of life. As is to be expected, prognosis and chances of recovery are also of major interest for patients, as is available support. Moreover, in contrast to the results for physicians and nurses, patients require detailed information about any effects their illness may have on family members.

4. Discussion

In this paper we have investigated the different user groups of a computerized clinical guideline, the process of formalizing such a guideline, as well as the clinical information that has to be integrated when executing the guideline. Based on the findings of a comprehensive literature research, we have focused on the information requirements of four different user groups.

We have examined a number of relevant studies about the information needs in clinical care as well as the modellers’ tasks involved in the development of a computerized clinical guideline. From these studies, we have derived:

1. A complete catalogue of every single aspect that may be related to information needs of any party concerned. Thus, we provide:
   - A comprehensive information source of categorized clinical information needs; because of the representation of uniform
findings from a variety of studies conducted in different countries; these findings are of general applicability.

- A consistent representation of important aspects of the step-wise procedure of modelling a CPG; this representation provides categorized findings of different studies and modelling approaches.

2 In particular, we provide detailed findings of specific information needs for each user group:

- We give an overview of tasks of guideline modellers, including the identification of knowledge elements and making them independent from the surrounding text, the modelling of clinical actions and the generation of vocabularies.
- Moreover, we give a comprehensive list of any information needs of physicians – physicians mainly seek information about treatment and medication.
- We give a comprehensive list of information needs of nurses; besides information about treatment and medication, they show an obvious need for information on psycho-social support for patients.
- Last but not least, we give a detailed outline of information that should be provided for patients; for instance, they require detailed information about effects on their future quality of life, about their specific prognosis and about chances of recovery.

By providing categorized information from several studies and publications, we establish an information basis necessary for the design of a useful software tool facilitating the formalization and the execution of a CPG. Depending on the potential and purpose of the individual tool, it may not be necessary (nor always possible) to include all of these tasks and information needs, but the decision as to which points to include and which to leave out can only be made on the basis of such an all-comprising list. We recommend that developers carefully consider every single aspect presented in this thesis, as all of these aspects have been formulated as modelling tasks or as actual information needs in clinical praxis.

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References


