



Generating expert and patient versions of medical guidelines from a single source

Applicants

Eligible proposals must have two (and only two) applicants from different disciplines within the Network Institute.

Supervisor Name	Department/Group	Faculty
1. V. Petit-Steeghs, (PhD student)	Athena Institute, VUA	FALW
2. Dr. Annette ten Teije	Dept. of Computer Science, VUA, Knowledge Representation and Reasoning group	FEW

Project description

Provide a brief description of the project (max. 300 words)

Current situation

Evidence based clinical guidelines are systematically developed statements to assist practitioners and patient decisions about appropriate health care for specific circumstances. They provide clinicians with health-care recommendations based on valid and up-to-date empirical evidence, they improve health-care outcomes and reduce health-care costs up to a 25%. Increasingly, such guidelines are not only developed by experts but also include the perspectives of patient organisations. Patient versions of clinical guidelines are increasingly developed to enhance shared decision making and to promote patient self-management.

The problem

The clinical guideline and its patient version are currently developed in isolation and the alignment of those versions is difficult both when developing and when updating the guideline.

Solution

We propose a method that is based on a generic computer model for guidelines from which we are able to generate a guideline version specific for different users (e.g. patients, experts, GPs and family members). We will investigate this method on a small scale by (1) modelling selected guideline fragments from expert and patient versions; (2) comparing the modelled fragments and (3) unifying these models in a single core-model (4) generate different version depending on the needs and wishes of the accompanying stakeholder groups.

New challenge

The main challenges of the proposed project are:

1. to use different vocabularies for guidelines (layman versus expert).
2. to identify the relation between guidelines fragments from expert and patient versions.
3. to model guideline fragments of expert and patient versions and their relation in a lightweight formal language such as a semantic wiki.

4. to design a generic representation of the guideline knowledge in such a way that both versions can be generated.

Project Organization

We request two academy assistants for 0.2fte each over the time of 1 year.

Required skills of candidate 1:

1. Skills in knowledge representation, such as those obtained by master students in the UvA/VU Artificial Intelligence MSc.
2. Basic skills in programming, data manipulation and data modelling, again compliant with the profile of our AI MSc students
3. General academic skills in executing reporting both in presentations and in writing
4. The candidate should be able to interact with medical domain experts and patient organisation for clarification on guidelines.

The Athena Institute and the KR&R group are already collaborating on the relation between patient versions and expert versions of clinical guidelines via a Lifestyle Informatics Bachelor student project. We and our current bachelor student would like to build on the results of the bachelor project in the form of this follow-up project. This means that we have already a candidate for this position.

Required skills of candidate 2:

1. Skills in interviewing and leading focus group discussions (being able to clarify questions, showing empathy and correct use of non-verbal communication), such as those obtained by master students in the MSc Management, Policy Analysis & Entrepreneurship in Health (MPA).
2. Basis skills in analyzing interview and focus group data by open and closed coding via for instance the computer program MAXqda.
3. Good English writing skills and general academic skills in executing a qualitative research project and reporting both in presentations and writing.
4. The candidate should have general knowledge on the health care system and have a clear interest in this domain.

A master student of the MSc Management, Policy Analysis & Entrepreneurship in Health (MPA) just started on the project 'Patient versions for Urological Cancer Guidelines' and could be a potential candidate for the position, in case of a positive evaluation of its research proposal.

Collaboration

Feasibility

Patient versions and expert versions of guidelines are publicly available via the websites of patient, professional and health care organisations as well as the richtlijndatabase.nl. Ms. Petit-Steeghs collaborates with two patient organisations in the development of patient versions for Urological Cancer Guidelines.

Expertise contributed by KRR:

The KRR groups has worked on medical knowledge representation since 1999. We are internationally recognised for our research in formalising medical guidelines, alignment of actual treatment and guideline, detection of interactions between guidelines, and checking whether the guideline is in accordance with quality indicators.

Challenges for KRR group: The KRR group has expertise on the expert version of guidelines, but not on patient version. Those patient versions often have additional information, eg. preferences of patients, and are aimed to be understood by non-experts. The challenge for us is the alignment of the different versions of the knowledge models (in this case patient/expert/GP/family guidelines) and ideally the generation of those models from one core-model.

Expertise contributed by Athena:

The Athena Institute has gained specific experience in patient and child participation in clinical guideline development (e.g. for haemodialysis and kidney disorders) and the inventory of the wishes and needs for patient and child versions of clinical guidelines from a patient and expert perspective (e.g. for work resumption

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after gynaecological complications and urological cancers). The perspectives of both patients and professionals on the development of patient versions of the clinical guidelines have been collected via semi-structured interviews and focus group discussions.

Challenges for Athena group: The Athena Institute has expertise on co-creating knowledge of various stakeholders on innovation processes. The perspectives of the stakeholders are visualized via qualitative research methods. For the Athena Institute the alignment of these qualitative outcomes into a more quantified generic model is of great interest.

Deliverables

Enumerate intended project results: papers, research proposals or otherwise. (max 200 words)

D1. Paper We will target the Knowledge Representation for Healthcare Workshop in the summer of 2017

D2. Demo showing the use of a semantic wiki to construct a knowledge model from which multiple guideline versions can be generated

D3. Project proposal for Phd position or post doc position Ideally the project will result in a proposal for a PhD project to be jointly submitted by Athena and the KR&R group.

Planning

Period	Tasks and Goals
Aug'16	Student 1&2: Selection of guideline fragments (expert & patient version) Student 2: set up stakeholder map and focus group design.
Sep'16	Student 1: Select expert & layman vocabularies Student 2: Arrange focus group discussions with stakeholders of the specific guideline.
Oct '16 - Nov'16	Student 1: Model and implement fragments of the guidelines and their relation Student 2: Conduct focus groups with stakeholders
Dec'16	Student 1: Generic guideline model and integrate preliminary results of the focus groups Student 2: Conduct focus groups with stakeholders
Jan'17-Feb'17	Student 1: Generate expert/patient versions based on the generic model Student 2: Conduct focus groups with stakeholders, analyze results and present preliminary results and the invitational conference of the project 'Urological Cancer Guidelines'
Mrt'17-April'17	Student 1: Build prototype Student 2: Analyze results and test these on prototype
May'17	Student 1&2: Write up for KR4HC workshop (document and release software)

Please respect the word count limits: proposals that exceed the stated limits will not be eligible.

Send completed proposals to: akademiestudent.fsw@vu.nl, before 10 June 2016 at 12.00pm. An independent committee will evaluate the proposals; subsequent notification of the committee decision will be given on 1 July.