Creating a Knowledge-Based Personal Patient Diary for Pediatric Cancer Survivors

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Introduction
- Pediatric cancer survivors face a lifetime of follow-up.
- It is important to engage patients in the design of their follow-up, and personalize it with respect to their conditions and preferences, as this will improve overall satisfaction [1, 2].
- We have developed the YouCan framework for facilitating Shared Decision Making (SDM) in pediatric cancer follow-up.
- The YouCan framework leverages the Guideline for Long Term Follow-Up for Survivors of Childhood, Adolescent, and Youth Adult Cancers [3].
- We extracted over 600 evidence-based rules for patient follow-up based on personal attributes and medical history.
- These rules govern the production of a Personal Patient Diary, a 5-10 page document given to patients detailing how they should proceed with their medical follow-up.

Shared Decision Making (SDM)
A patient-centered care paradigm where clinicians and patients leverage the best available evidence to make decisions together about the best management of their care [4].

- Engaging patients in the care process leads to better communication, better task orientation and improvement of quality of life [4].
- A key aspect of SDM is the incorporation of evidence.
- In a SDM setting the pertinent aspects of the relevant Clinical Practice Guideline (CPG) are discussed with the patient.
- Health informatics technologies can be exploited to develop evidence-based personalized self-management programs that deliver on-demand, individualized educational content in a private learning environment.
- Personalized educational interventions are more likely to be read, remembered and experienced as relevant [5, 6, 7].

YouCan Framework

CPG (Clinical Practice Guideline) execution engine

- We have taken a healthcare knowledge management approach to the design of the YouCan framework [8].
- Semantic web based technologies have been developed to establish an evidence-based SDM system.
- We computize the CPG on Long Term Follow-Up for Youth Adult Cancers and dynamically compose a personalized patient diary.

CPG Computerization
- We used our own ontology [9] to computerize the follow-up CPG, resulting in the YouCanOntology (in OWL-DL).
- An example of a rules page from the CPG is given below.

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CHEMOTHERAPY
ANTI-FUNGAL ANTIMICROBIALS
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Execution Engine
- The execution engine takes the rules base and injects patient information into a Pallet reasoner.
- Personal attributes, Disease conditions, past and current therapeutic agents and risk factors are pulled from the patient database and incorporated into the diary.
- The diary is embedded within the Cancer in Young People in Canada (CYP-C) portal.
- Executed using C# and ASP.NET.

Diary Composition
- The results of the CPG execution are embedded within an automatically generated doc file.
- The following sample report is for a patient diagnosed with Acute Myeloid Leukemia in March 2001 who was 15 years old.
- He received chemotherapy, radiotherapy and surgery, starting in January 2001 and ending in December 2004.
- The report is presented in 6 sections: Introduction and diagnosis information, Treatment, CPG-based follow-up instructions, Disease information, Treatment Information, General follow-up directions and tools.

Evaluation and Future Work
- In phase 1, domain experts evaluated the SDM rules for their clinical validity.
- In phase 2, the execution of the rules was evaluated to ensure completeness and consistency of the execution results. Sample clinical cases were used as input to the CPG execution engine and the resulting diaries were evaluated.
- In phase 3, the composed patient diary will be field tested by practicing oncologists and nurses to evaluate the messaging content and diary layout.
- As a final evaluation step, we are planning a pilot study involving cancer survivors from the WWK who will be provided their personalized diary to evaluate the diary's impact on their self-management.

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References
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