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

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Introduction

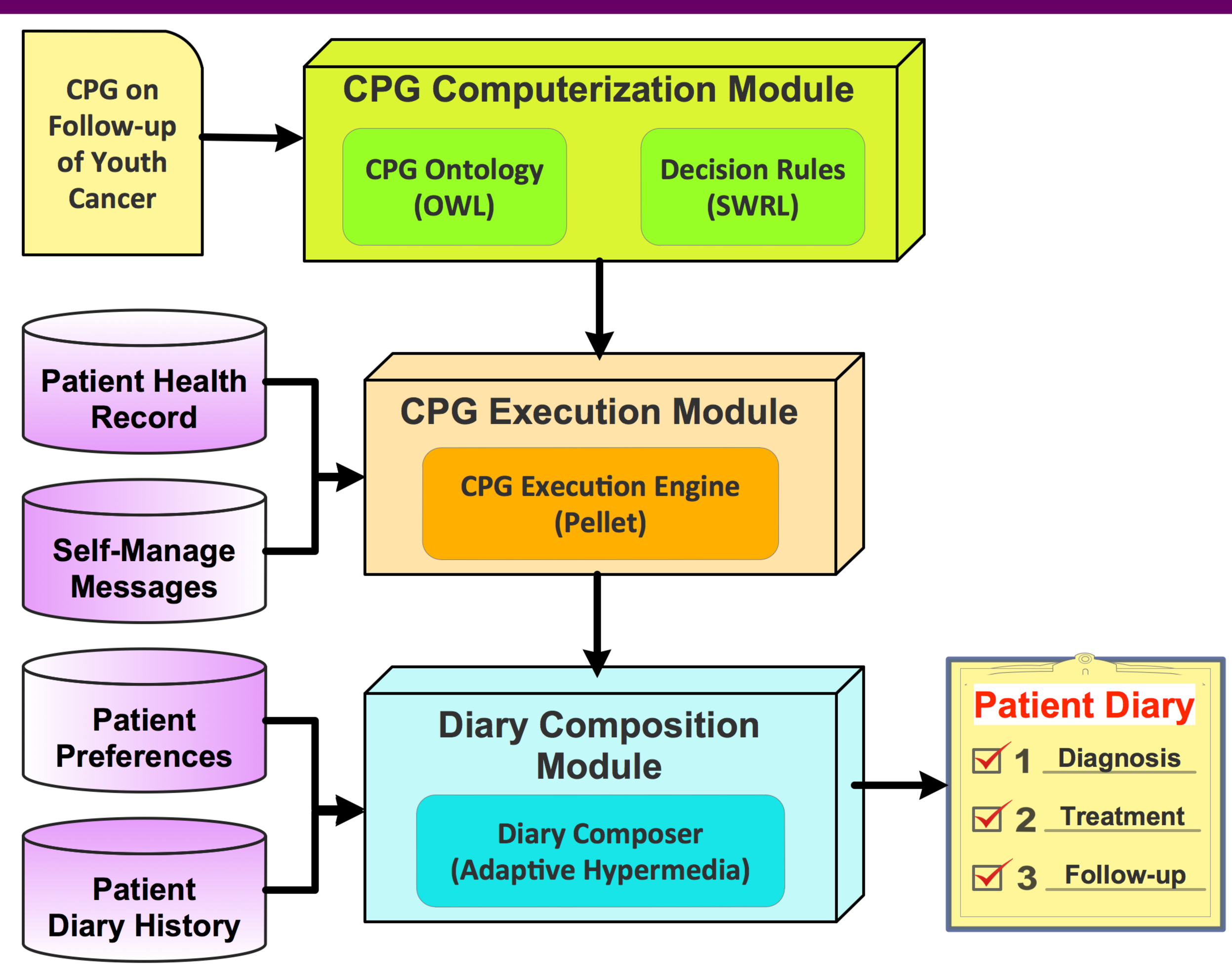
- Pediatric cancer survivors face a lifetime of follow-up
- It is important to engage patients in the design of their follow-up, and personalize it with respect to their conditions and preferences, as this will improve overall satisfaction [1, 2].
- We have developed the *YouCan* framework for facilitating 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** [8]
- 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 [3].

- 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]

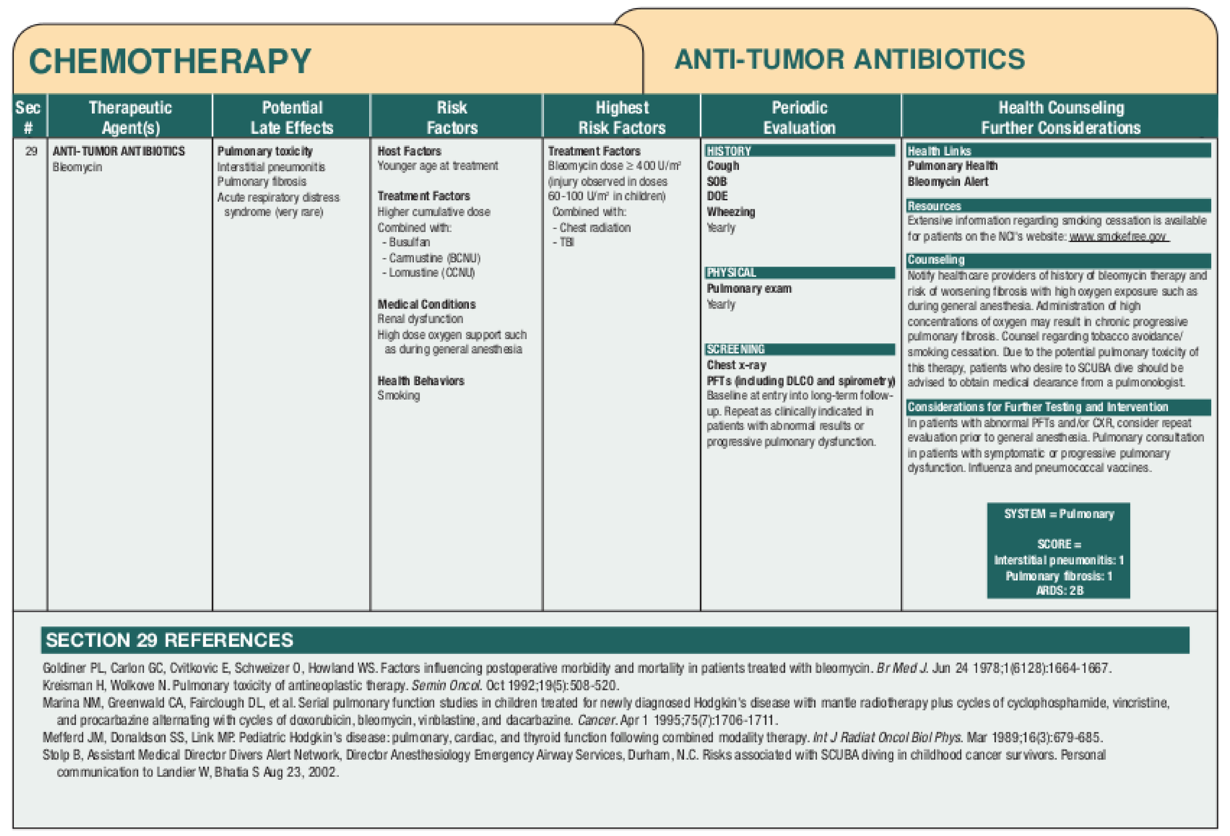
YouCan Framework



- We have taken a healthcare knowledge management approach to the design of the *YouCan* framework [9]
- Semantic web based technologies have been developed to
  1. establish an evidence-informed SDM session
  2. computerize the CPG on Long Term Follow-Up for Youth Adult Cancers
  3. dynamically compose a personalized patient diary

CPG Computerization

- We used our own ontology [10] to computerize the follow-up CPG, resulting in the *YouCan* Ontology (in OWL-DL)
- An example of a rules page from the CPG is given below



CHEMOTHERAPY — ANTI-TUMOR ANTIBIOTICS

Sec #	Therapeutic Agent(s)	Potential Late Effects	Risk Factors	Highest Risk Factors	Periodic Evaluation	Health Counseling Further Considerations
29	ANTI-TUMOR ANTIBIOTICS Bleomycin	Pulmonary toxicity: Interstitial pneumonitis, Pulmonary fibrosis, Acute respiratory distress syndrome (very rare)	Host Factors: Younger age at treatment. Treatment Factors: Higher cumulative dose; Combined with: - Busulfan - Carmustine (BCNU) - Lomustine (CCNU). Medical Conditions: Renal dysfunction; High dose oxygen support such as during general anesthesia. Health Behaviors: Smoking	Treatment Factors: Bleomycin dose ≥ 400 U/m² (injury observed in doses 60-100 U/m² in children); Combined with: - Chest radiation - TBI	HISTORY: Cough, SOB, DOE, Wheezing; Yearly. PHYSICAL: Pulmonary exam; Yearly. SCREENING: Chest x-ray; PFTs (including DLCO and spirometry): Baseline at entry into long-term follow-up. Repeat as clinically indicated in patients with abnormal results or progressive pulmonary dysfunction.	Health Links: Pulmonary Health, Bleomycin Alert. Resources: Extensive information regarding smoking cessation is available for patients on the NCI's website: www.smokefree.gov. Counseling: Notify health care providers of history of bleomycin therapy and risk of worsening fibrosis with high oxygen exposure such as during general anesthesia. Administration of high concentrations of oxygen may result in chronic progressive pulmonary fibrosis. Counsel regarding tobacco avoidance/smoking cessation. Due to the potential pulmonary toxicity of this therapy, patients who desire to SCUBA dive should be advised to obtain medical clearance from a pulmonologist. Considerations for Further Testing and Intervention: In patients with abnormal PFTs and/or CXR, consider repeat evaluation prior to general anesthesia. Pulmonary consultation in patients with symptomatic or progressive pulmonary dysfunction. Influenza and pneumococcal vaccines. SYSTEM = Pulmonary; SCORE = Interstitial pneumonitis: 1, Pulmonary fibrosis: 1, ARDS: 2B

SECTION 29 REFERENCES

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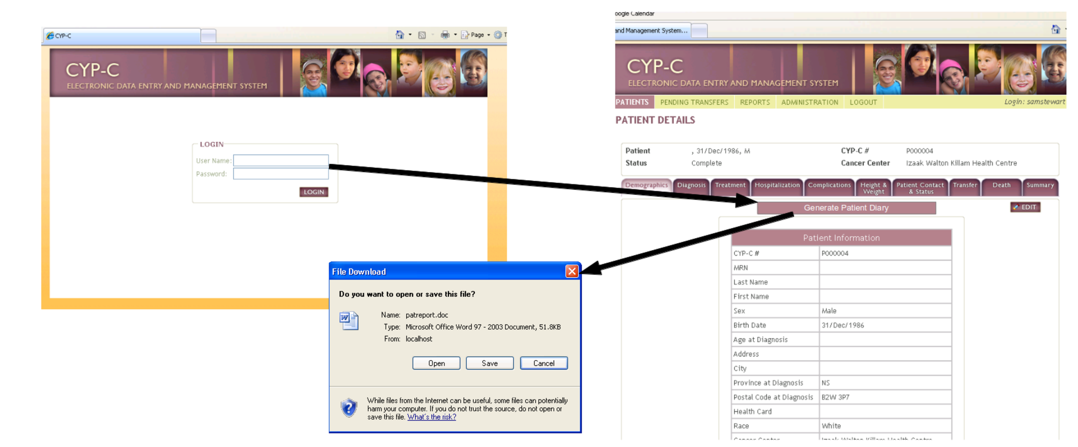
- Each page in the CPG contains an agent, a complication, risk factors for the complication, monitoring and prevention guidelines and a set of references
- The information is extracted from this page and constituted as a set of rules, such as the rules below for the drug Bleomycin

DRUG: BLEOMYCIN	
Things to know	Bleomycin can affect lung function by causing pulmonary fibrosis (scarring)
What you need to do	Keep your lungs as healthy as possible Don't smoke Avoid dusty and fumey places Tell your doctor if you develop a cough or wheeze that lasts more than a week or if you feel short of breath or breathless when exercising
Decision Points	
IF age $>$ 10 yrs at treatment AND dose $<$ 400 units/m2	Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year.
IF age $<$ 10 years at treatment OR dose $>=$ 400 units/m2 OR received chest irradiation OR received Busulfan, BCNU or CCNU	Ask your doctor to do a baseline breathing test (including peak flow, diffusion capacity and spirometry) Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year. Ask your doctor to repeat your breathing test every 5 years or so - or when he or she thinks there is a clinical need

- The *YouCan* Ontology serves as the basis for the formalization of the SDM rules
- The premise of the SDM rule includes a specific therapeutic agent (i.e. a drug) together with a set of patient attributes and preferences
- The body of a rule contains CPG-based follow-up recommendations for the patient based on the medical history, classified into three types
  1. disease information that patients need to know (such as negative outcomes)
  2. what actions to take in specific situations
  3. specific issues to discuss with the GP

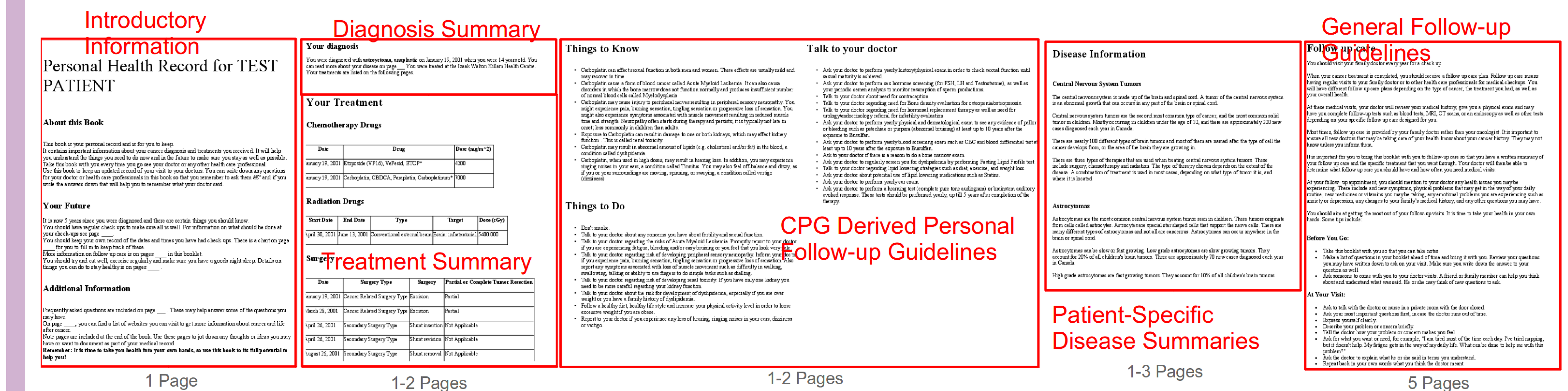
Execution Engine

- The execution engine takes the rules base and injects patient information into a Pellet 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 Astrocytoma in March 2001 when he 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 message content and diary layout.
- As a final evaluation step, we are planning a pilot study involving cancer survivors from the IWK who will be provided their personalized diary to evaluate the diarys impact on their self-management.

Discussion

- Home-based management of pediatric cancer survivors is a challenging undertaking, as it demands adherence to the follow-up plan by young patients.
- The use of SDM principles allows opportunities to engage youth survivors in their care plan.
- We have presented a semantic web based *YouCan* framework that facilitates the formulation of a personalized self-management diary
- The diary is being embedded within the CYP-C portal so that the service can be extended to youth survivors across the country.
- We plan to deliver the survivors self-management diary through a secure web app that will be accessible to survivors by mobile devices.

Acknowledgments

This project is funded by a catalyst grant from Canadian Institutes of Health Research

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