

# Collaborating with Youth to Inform and Develop Tools for Psychotropic Decision Making

Andrea Murphy BScPharm, ACPR, PharmD<sup>1,2,3</sup>; David Gardner BScPharm, ACPR, PharmD, MSc<sup>3</sup>; Stan Kutcher BA, MA, MD, FRCP(C)<sup>2,3,4,5</sup>; Simon Davidson MB, BCh, FRCP(C)<sup>6,7</sup>; Ian Manion PhD, CPsych<sup>6,8</sup>

## Abstract:

**Introduction:** Youth oriented and informed resources designed to support psychopharmacotherapeutic decision-making are essentially unavailable. This article outlines the approach taken to design such resources, the product that resulted from the approach taken, and the lessons learned from the process. **Methods:** A project team with psychopharmacology expertise was assembled. The project team reviewed best practices regarding medication educational materials and related tools to support decisions. Collaboration with key stakeholders who were thought of as primary end-users and target groups occurred. A graphic designer and a plain language consultant were also retained. **Results:** Through an iterative and collaborative process over approximately 6 months, Med Ed and Med Ed Passport were developed. Literature and input from key stakeholders, in particular youth, was instrumental to the development of the tools and materials within Med Ed. A training program utilizing a train-the-trainer model was developed to facilitate the implementation of Med Ed in Ontario, which is currently ongoing. **Conclusion:** An evidence-informed process that includes youth and key stakeholder engagement is required for developing tools to support in psychopharmacotherapeutic decision-making. The development process fostered an environment of reciprocity between the project team and key stakeholders.

**Key words:** (MeSH terms): psychopharmacology, decision making, youth, young adult

## Résumé

**Introduction:** Il n'existe pratiquement pas de ressources destinées aux adolescents qui soient à jour et qui puissent être appliquées à la prise de décisions psychopharmacothérapeutiques. Cet article présente la méthode utilisée pour concevoir ces ressources, le résultat obtenu et les enseignements tirés de ce processus. **Méthodologie:** Étude, par une équipe de spécialistes en psychopharmacologie, des meilleures pratiques sur le matériel de formation et les outils connexes d'appui aux décisions. Collaboration avec les principaux utilisateurs finals et les groupes cibles. Recours aux services d'un dessinateur graphique et d'un langagier. **Résultats:** Collaboration à l'établissement de la terminologie et à un passeport de formation médicale en six mois. L'étude de la littérature et les commentaires des intervenants clés, notamment des adolescents, ont été essentiels à la conception des outils et du matériel de formation médicale. Ce programme, qui est basé sur le modèle de formation du formateur, est actuellement appliqué en Ontario. **Conclusion:** La conception d'un outil décisionnel psychopharmacothérapeutique passe nécessairement par l'approche factuelle. Ce processus encourage l'interaction entre les membres de l'équipe chargée du projet et les utilisateurs finals.

**Mots clés:** (terminologie MeSH): psychopharmacologie, prise de décisions, adolescent, jeune adulte

<sup>1</sup> School of Nursing, Dalhousie University, Halifax, Nova Scotia

<sup>2</sup> Sun Life Financial Chair in Adolescent Mental Health, Dalhousie University, Halifax, Nova Scotia

<sup>3</sup> Department of Psychiatry, Dalhousie University, Halifax, Nova Scotia

<sup>4</sup> IWK Health Centre, Halifax, Nova Scotia

<sup>5</sup> WHO Collaborating Centre, Dalhousie University, Halifax, Nova Scotia

<sup>6</sup> The Provincial Centre of Excellence for Child and Youth Mental Health at the Children's Hospital of Eastern Ontario, Ottawa, Ontario

<sup>7</sup> Department of Psychiatry, University of Ottawa, Ottawa

<sup>8</sup> School of Psychology, University of Ottawa, Ottawa

Corresponding Email: andrea.murphy@dal.ca

## Introduction

Sharing in psycho-pharmacotherapeutic decision-making requires that youth and their caregivers be informed and able to exchange information with health care providers. This process is dynamic and requires collaborative information seeking and sharing, consensus building, and goal setting (Samele, Lawton-Smith, et al., 2007; Shaw, 2001). However, research has shown that in general, patients often receive inadequate information regarding medications in their encounters with health providers (Bell, Whitehead, et al., 2006; Gardner, Murphy, et al., 2001; Wiederholt, Clarridge, et al., 1992) and that some clinicians are inclined toward information sharing sessions that are brief and limited in detail (Raynor, Blenkinsopp, et al., 2007) despite patients' wishes for extensive discussions focusing on important factors such as the potential harms of treatment (Gardner, MacKinnon, et al., 2007). Ideally, tools that can facilitate meeting decisional needs and lead to quality decisions that promote safe and effective medication use should be available (Nathan, Zerilli, et al., 2007; Raynor, Blenkinsopp, et al., 2007; Wolf, Davis, et al., 2006).

Substantive research in the area of health education materials and decision aids that support decision-making has occurred in recent decades (Craven, Nikolaou, et al., 2005; Dickinson, Raynor, et al., 2001; Dickinson & Raynor, 2003; Elwyn, O'Connor, et al., 2006; Koo, Krass, et al., 2006; Koo, Krass, et al., 2005; Nathan, Zerilli, et al., 2007; Nicolson, Knapp, et al., 2006; O'Connor, 2006; O'Connor, Bennett, et al., 2009; Raynor, Savage, et al., 2004; Raynor, Blenkinsopp, et al., 2007; Wolf, Davis, et al., 2006; Zwaenepoel & Laekeman, 2003). For example, the International Patient Decision Aid Standards Collaboration has developed a checklist for developing and evaluating decision aids (Elwyn, O'Connor, et al., 2006). Frameworks regarding decision support have also been developed. The Ottawa Decision Support Framework for example asserts that a participant's decisional needs affect the quality of their decisions (O'Connor, 2006). Decisional needs in this framework include characteristics about the decision itself, decisional conflict, knowledge and expectations, values, support and resources, and personal and clinical characteristics of the patients and practitioners (O'Connor, 2006). Decision supports in this framework take several forms (e.g., decision aids) and help to resolve unmet decisional needs. These initiatives are a step in the right direction but tools for supporting youth faced with decisions regarding psychotropic treatment are effectively non-existent.

Recognizing that medication information resources and tools to support youth with mental illnesses in making decisions with respect to psychopharmacology were absent for youth in

care, the Ministry of Child and Youth Services (MCYS) in Ontario, Canada sought to have such resources developed. The target users for the resources include:

- 1) youth aged 12 to 24 for whom psychotropic treatment is being considered or is ongoing to treat mental symptoms or a mental illness;
- 2) caregivers including family and youth workers, and
- 3) health providers, such as physicians, pharmacists, nurses, psychologists, occupational therapists, and social workers.

This article describes the approach used to develop youth informed resources, the product that resulted from the approach, and lessons learned from the process.

## Methods

### ***Building a team to develop youth oriented tools with relevance***

A project team with extensive knowledge (explicit and tacit) of psychopharmacology and education of health care professionals and consumers was assembled.

### ***Tool development***

Over a six-month period beginning in November 2006, the project team developed a paper-based tool called Med Ed and the Med Ed Passport. A scoping review of the literature regarding the best available evidence on theoretical underpinnings, guiding principles and tenets (Table 1) for developing medication education materials and decision support tools was conducted. Following this, the project team:

- outlined key principles for safe and effective psychotropic use;
- utilized relationship capital to organize and conduct two, approximately two hour focus groups with youth with mental illnesses. One group included youth aged 12 to 16 and the other included youth aged 18 to 25;
- utilized relationship capital to organize and conduct focus groups and interviews with key stakeholders such as health care providers. Interviews were held with primarily hospital-based health care providers and a focus group was held for approximately eight community based health care providers;
- created an iterative process for feedback and review following stakeholder encounters;
- contracted a graphic designer, who also attended youth focus groups, and a plain language consultant for design and literacy elements, respectively;
- participated in a peer review process with the MCYS and an expert review panel. The Ontario Expert Panel on psychotropics has a mandate to develop standards of care for the administration of psychotropics in residential settings.

**Table 1. Guiding principles for constructing psychotropic education and related tools for youth****Risk and Benefit communications**

- Although challenging, providing evidence regarding benefits and risks to patients in a meaningful way is necessary so that they can be well informed (Hope, 2002).
- Unlike therapeutic content areas such as immunizations (Fredrickson, Davis, et al., 2001), there is no information regarding the impact of discussing treatment benefits and risks in youth and none for those with mental illnesses.
- Communication of risks can be difficult as baseline knowledge of youth about medications can vary markedly depending on various characteristics including but not limited to cognitive abilities, developmental stage, previous experiences, and illness severity (Hameen-Anttila, Juvonen, et al., 2006). Similarly, these factors can influence how information is interpreted, valued, and subsequently used by patients in making decisions about their treatments (Rappaport & Chubinsky, 2000; Shaw, 2001).
- Regardless of the age or medical condition, there is generally a lack of consensus about the best way to communicate risks (e.g., number needed to harm, incidence, relative risk, absolute risk) and benefits (e.g. number needed to treat, relative risk reduction, absolute risk reduction) of therapies (Berry, Knapp, et al., 2006; Halvorsen, Selmer, et al., 2007; Knapp, Raynor, et al., 2004).
- Input from patients regarding their preferences for risk communication demonstrates that numeric representation combined with or in lieu of verbal or qualitative descriptors is important and often preferred (Davis, 2007; Halvorsen, Selmer, et al., 2007; Man-Son-Hing, O'Connor, et al., 2002; Raynor, Blenkinsopp, et al., 2007).

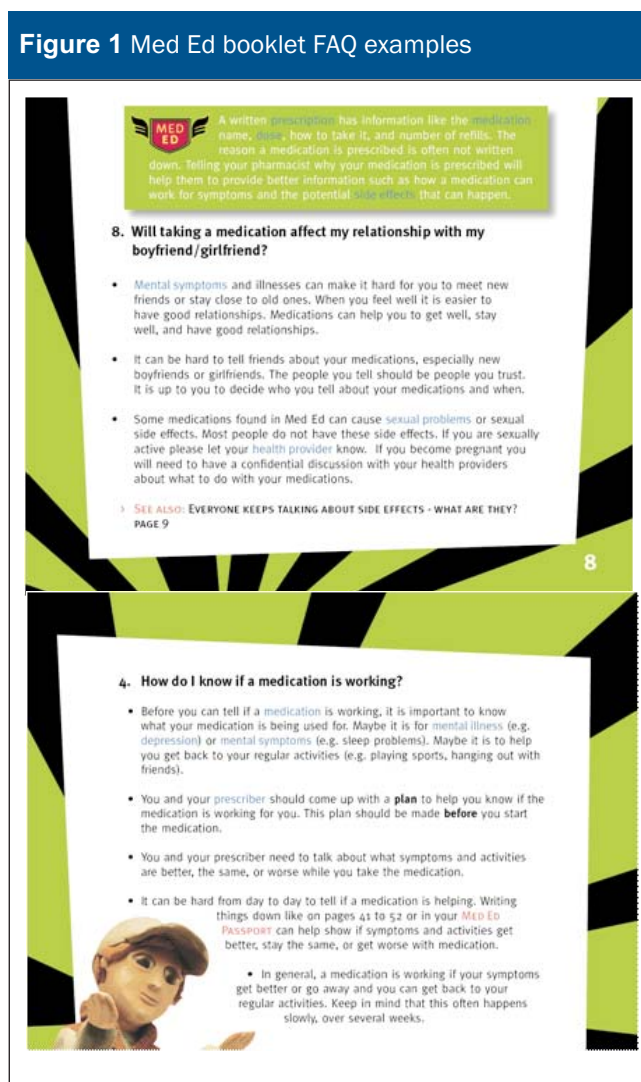
**Choosing the delivery vehicle for medication information**

- Youth and other consumers frequently default to the Internet to find health and medication information (Diaz, Griffith, et al., 2002; Hansen, Derry, et al., 2003; Sciamanna, Clark, et al., 2003).
- The use of the Internet for medication information can be challenging because of potential lack of youths' ability to evaluate websites, overwhelming information volume, uncertain credibility, incomplete information, inappropriate literacy levels, and the potential for those with medical conditions to be taken advantage of, is not uncommon with use of the Internet (Peterson, Aslani, et al., 2003).
- Some research demonstrates patients rarely share or discuss information that they have found on the Internet with their health providers (Diaz, Griffith, et al., 2002).
- The literature regarding medication information needs suggests that patients still prefer to receive verbal and/or printed materials as their primary source of medication information (Raynor, Blenkinsopp, et al., 2007; Zwaenepoel, Bilo, et al., 2005).
- Despite information technology advances, clinicians still tend to prefer face-to-face interactions and paper-based resources before computer-based technologies (Bennett, Casebeer, et al., 2005; Bennett, Casebeer, et al., 2006; Murphy, Fleming, et al., 2006).

**Using explicit and tacit knowledge to inform content and design**

- Patients prefer to have access to detailed information about their treatment options (Gardner, MacKinnon, et al., 2007; Raynor, Blenkinsopp, et al., 2007)
- Research regarding the design, use, and impact of written medication information has been a priority for many groups (Craven, Nikolaou, et al., 2005; Dickinson, Raynor, et al., 2001; Dickinson & Raynor, 2003; Elwyn, O'Connor, et al., 2006; Koo, Krass, et al., 2006; Koo, Krass, et al., 2005; Nicolson, Knapp, et al., 2006; O'Connor, 2006; O'Connor, Bennett, et al., 2009; Raynor, Savage, et al., 2004; Raynor, Blenkinsopp, et al., 2007; Zwaenepoel & Laekeman, 2003; Zwaenepoel, Bilo, et al., 2005).
- A body of work is available outlining techniques for constructing medication information sources. Typically, information regarding format (e.g. font size, paper weight), suggested literacy levels, and even information on where to place materials is readily available (Craven, Nikolaou, et al., 2005; Davis, Wolf, et al., 2006; Davis, Wolf, et al., 2006; Koo, Krass, et al., 2006; Koo, Krass et al., 2005; Wolf, Davis, et al., 2006).
- Having appropriate literacy levels is consistently made as a recommendation and is well supported with evidence (Davis, Wolf, et al., 2006; Davis, Wolf, et al., 2006; Wolf, Davis, et al., 2006). However, evidence to support other recommendations for optimizing the use of patient education or written drug information materials is weak or inconsistent. As an example, pictures or pictograms to demonstrate or explain the use of medications has been suggested as a helpful tool in promoting safety but several authors have demonstrated results to the contrary (Davies, Haines, et al., 1998; Knapp, Raynor, et al., 2005).
- Medication information resources, even when based on best practices and evidence, may not be read by consumers and therefore cannot support informed autonomous or shared decision-making (Nathan, Zerilli, et al., 2007).
- Considering what kinds of information that specific patient groups want, need, and value is imperative to developing these tools (Dickinson, Raynor, et al., 2001; Dickinson & Raynor, 2003; Nicolson, Knapp, et al., 2006; Raynor, Savage, et al., 2004; Zwaenepoel & Laekeman, 2003; Zwaenepoel, Bilo, et al., 2005).
- Consumer input is heavily emphasized in emerging collaborative care models where the theme of consumer centeredness encourages involvement in all aspects of care including treatment decisions, designing educational materials, and program evaluations (Gagne, 2005).
- Several authors have shown that what clinicians think is important information about medications and treatment is not necessarily what patients value (Davis, 2007; Gardner, MacKinnon, et al., 2007; Raynor, Blenkinsopp, et al., 2007; Zwaenepoel, Bilo, et al., 2005).

Figure 1 Med Ed booklet FAQ examples



## Results

### ***Med Ed and Med Ed Passport: Narrowing the chasm for available, youth-oriented and informed psychotropic information tools***

Med Ed has 88 pages covering eight main sections including

1. 26 frequently asked questions (FAQs) with concise bulleted responses;
2. psychotropic information on the major psychotropic drug classes;
3. monitoring tools (“*trackers*”) for symptoms, activities, and side effects;
4. checklists of questions to ask doctors and pharmacists, and one about blood monitoring;
5. a medication log/list;
6. an appointment log;
7. a notes section; and
8. a glossary.

Youth in focus groups preferred detailed information about psychotropics in the booklet and suggested the development of a portable, inconspicuous companion. Subsequently, the 56-page Med Ed Passport was developed, which mirrors the booklet but is populated with trackers, condensed checklists and FAQs, a notes section, and logs for appointments and medications. Portability was as an important characteristic for youth and the pocket-size allows for easy transport to each health provider encounter. Selected images and content of the Med Ed booklet and passport are provided in figures 1 to 3.

### ***Lessons learned: youth are the key***

Youth input on content, structure, visual representations, and organization of Med Ed was critical to its development. The relationships amongst the project team and key stakeholders were not only consultative but also collaborative. It was apparent that the project development team and expert clinician reviewers’ opinions were frequently incongruent with that of the youth. For example, the value of consumer input was reflected in the first focus group when participants were shown some initial ideas for design and graphics. One youth participant astutely described one of the designs, one preferred by the project team, as “too hospital” and conveying a negative image due to its association with hospital-based materials.

It also became evident from various sources (e.g., research and lack thereof, literature, focus group participants) that youth with mental illness experience disparities in having decisional needs met and are at risk of having minimal involvement in pharmacotherapeutic decision making and premeditated, collaborative monitoring. Youth relayed to the project team that they thought a resource such as the one being developed was certainly needed and that they valued being a part of the process.

The youth in focus groups encouraged a “frequently asked question” format for most content and also suggested inclusion of multiple monitoring tools and checklists. These FAQs and checklists are designed to act as springboards to information seeking and sharing. Several themes about basic principles of medication use were used in the FAQs to allow users to assess values regarding the importance of particular issues. As an example, the FAQ, “*How does my prescriber know which medication to give?*” addresses treatment selection. This question outlines principles that prescribers typically consider in medication selection and encourages youth to be an active participant in the treatment selection process. Participants dialogued about what the answer to this question should include. Several youth felt that the process of treatment selection was often ambiguous and youth were often

Figure 2. Med Ed booklet medication review example

### ANTIDEPRESSANTS

**Commonly used for:**  
Problems with mood (e.g. depression), anxiety disorders (e.g. generalized anxiety disorder, obsessive compulsive disorder, panic disorder, post traumatic stress disorder), eating disorders, and sleep problems. These medications also have many other uses. Please talk to your prescriber or pharmacist for more information on other uses.

**How these medications work:**  
Antidepressants have been shown to increase the activity of several chemicals (or "neurotransmitters") and targets (or "receptors") in the brain. Examples of some of the chemicals are serotonin and noradrenaline.

**How do I know if it is working?**  
Before you start to take an antidepressant, you should talk to your prescriber about the symptoms you have and when they should start to improve. Your prescriber and other health providers should come up with a plan of how to track these symptoms with you (see boxes 41 to 46). It is a good idea to write down symptoms and activities so that you and your health providers can tell if the medication helps make them better.

It is important to know that antidepressants can cause some side effects before you notice that your symptoms are getting better. This picture shows that after starting an antidepressant the side effects (red line) are more likely to happen at first and will eventually go down in time. The benefits (green line) of the medication also increase as time goes by (e.g. improving mood, sleep, energy, reducing anger).

**SIDE EFFECTS:**  
**Common:** The picture on the next page shows some common side effects that can happen with some of the antidepressants. Different groups of antidepressants have different side effects.

### ANTIDEPRESSANTS

Show this picture to your prescriber and discuss which side effects may apply to the medication prescribed for you. Ask your prescriber to tell you about any uncommon but potentially harmful side effects that can happen. Talk about when and how to watch for side effects and about what to do if side effects happen. You can make notes about this information on pages 69 to 74, or in your **MED ED PASSPORT**.

**Uncommon but could be serious or harmful:**  
Changes in mood including unusual happiness, feeling irritable, cranky, or feeling excited.  
Thoughts about hurting yourself or suicide.  
Abnormal bleeding.  
Serotonin syndrome which can have symptoms such as fever, sweating, problems with reflexes, shaking, problems with balance and movements, and confusion.

**When and who to ask for help:**  
You should ask for help any time you have a question about your illness, symptoms, or medication. It is very important that you ask for help if you think you are having side effects or feel that your medication is not working. If you take an antidepressant, you should ask your health providers about a plan for regular appointments to see how you are doing on your medication. You should also ask about who to call in an emergency.

**Important things to consider about these medications:**  
In recent years, there has been a lot of news about the side effects and risks of antidepressants. If you have thoughts of hurting yourself before starting or during treatment with an antidepressant, it is important to tell health providers, especially your prescriber. These medications can help to decrease these thoughts in most people. Uncommonly, these feelings can become stronger or more intense early in treatment for some people.  
It is important to talk to health providers about the benefits and risks of treatment.  
Do not stop these medications quickly or "cold turkey" as side effects or a withdrawal reaction can happen. Although this reaction is not dangerous it can make a person feel very unwell.

Figure 3. Med Ed passport tools examples

#### SYMPTOM TRACKER

Write down 3 symptoms that bother you. Rate each symptom using the happy and sad face scale. Talk to your health providers about how often to do this (such as once a week). Take this to each visit with your health providers.

Current medication names and doses:

SYMPTOM 1:

Dates	worse	no change	better
	☹️	😊	😊😊
	☹️	😊	😊😊
	☹️	😊	😊😊

#### ACTIVITY TRACKER

Write down 3 things that you would like to do better but can't because you feel unwell. These might be getting better grades at school, hanging out with friends, playing music, or playing soccer. Rate each activity using the happy and sad face scale. Talk to your health providers about how often to do this (such as once a month). Take this to each visit with your health providers.

Current medication names and doses:

ACTIVITY 1:

Dates	worse	no change	better
	☹️	😊	😊😊
	☹️	😊	😊😊
	☹️	😊	😊😊

#### SIDE EFFECT TRACKER

Write down the 5 side effects that bother you most. Rate each side effect using the happy and sad face scale. Talk to your health providers about when to do this (such as once a week). Take this to each visit with your health providers.

Current medication names and doses:

SIDE EFFECT 1:

Dates	worse	no change	better
	☹️	😊	😊😊
	☹️	😊	😊😊
	☹️	😊	😊😊

SIDE EFFECT 2:

Dates	worse	no change	better
	☹️	😊	😊😊
	☹️	😊	😊😊
	☹️	😊	😊😊

#### CHECKLIST

Use this checklist when first starting a medication or at any time during your treatment to help you get the information you need from your doctor and pharmacist. You can share this information with other health providers.

Question	Notes and tasks
What is the name of the medication?	
How do I take this medication?	
When do I take this medication?	
How long will it take for the medication to help me feel better?	
How will this medication help me?	
What side effects can happen?	
When do they happen?	
Are there any serious side effects that I should know about?	
What do I do if I have a side effect?	

#### MEDICATION LIST

Write down all medications. Some examples are given in the table.

Medication name	What for?	Strength/ Dose	How and when I take this medication	Date started	Date stopped	If stopped, why?	Side effects (see 4)	Other notes (e.g. side effect information, when medication looks bad)
Risperidone	Tics	0.5 mg	Once a day at bedtime	June/06		✓	☹️	Shaky hands. Take right before bed - if makes me sleepy.
Salmeterol (blue inhaler)	Asthma	2 puffs	When I need it & before I run	2006?		✓	☹️	Take a half hour before running. Shaky hands.

unaware of why they were offered one treatment over another. These comments corroborated other sentiments that treatment decisions may not consistently be made in collaboration or even in consultation with youth. The FAQs such as “*What can I expect when I start a medication?*,” “*How long will it take a medication to make me feel better?*,” “*How do I know which dose is right for me?*,” were framed to help with discussing treatment expectations and were thought to be of primary importance by youth. Focus group participants recommended that these questions be placed early in the booklet. Other FAQs recommended by participants such as, “*I am feeling better. Should I stop my medication?*,” aim to promote the safe and effective use of psychotropics as well as the importance of adherence and what to think about when considering whether to continue a medication.

The monitoring tools or “trackers” for symptoms, activities, and side effects encourage a collaborative plan for monitoring the effects of psychotropics. These tools are to be personalized by jointly determining which symptoms, activities, and side effects are most important and therefore merit a systematic approach to tracking. Trackers facilitate both patient and caregiver monitoring over treatment and act as an efficient source of information for assessing progress between visits. Youth focus group participants were in favor of simple and easy to follow, graphically simplistic, monitoring tools that could be easily reviewed with health care providers and thought this approach was novel. Comments from group members indicated that the approach to monitoring their individual performance and response to medications would be beneficial and important for their wellness maintenance.

Given the need for clear information about risks of treatment alternatives, Med Ed was designed with an FAQ, “*Everyone keeps talking about side effects—what are they?*.” The content of the side effect FAQ introduces the topic of risks and gives a pictorial example of side effects frequencies such as 0.1, 1, and 10 percent. Key questions for side effects such as when do they occur, what to expect, what to do about it, how serious it can be, and what to expect when treatment is stopped are included. Feedback from focus groups suggested that adverse reactions to medications were not always clearly articulated or discussed according to individual values and preferences. There was indication that some youth would have changed their decisions regarding taking treatments if they had known the explicit benefits and risks of some therapies. Additionally, in light of psychotropic controversies (e.g., SSRIs and suicidality) Med Ed contains two FAQs attempting to address some of these issues: “*Approved indications*” and “*off label use*” - *what do they mean?*; and *What is a black box warning?*.

Med Ed’s initial format is paper-based given that clinicians and patients continue to value this format and that computer access may be unavailable for some (e.g., youth without a fixed address may have inconsistent access or those living in rural or remote communities without Internet access). Focus group participants were in favor of paper-based distribution but agreed that an Internet accessible version would be a logical next step. An Internet based version can be readily adapted and is planned. An FAQ, “*Can I trust medication information from the Internet?*,” also briefly outlines some of the challenges with information available on the Internet and gives guidance for patients using the Internet for medication-related information.

A French translation of Med Ed (edu Medi) has been completed and exploration of translation for other languages (e.g., Spanish, Portuguese) has begun.

### **Med Ed future directions: distribution and evaluation**

A Med Ed training program using a train-the-trainer model has been developed. A two day training program for 20 champion trainers was delivered in May of 2008. The training program materials included a binder with presentations of the theory and development processes for Med Ed, information on informed consent, pre tests, post tests, and 2 application cases studies using Med Ed, group exercises, and networking opportunities to help foster a community of practice. The project team acknowledged that the successful implementation of Med Ed would depend on appropriate facilitation into practice areas with an awareness of the contexts of practices. As such the training sessions included group exercises in which participants considered possible barriers and facilitators to the use of the resource in specific practice settings and discussed possible strategies and solutions. As Med Ed is not intended to be a stand-alone tool, the training programs also provides information on scopes of practice, roles and responsibilities, and competencies related to psychopharmacology of health providers in the mental health system. A website was developed to support these individuals in a virtual community of practice. A Med Ed “training light” version was developed for champion trainers to move forward in training other key stakeholders (e.g., front line clinicians). These training programs are supported by the Provincial Centre of Excellence for Child and Youth Mental Health.

The impact of Med Ed on a variety of outcomes (e.g., knowledge, satisfaction, treatment acceptance and adherence) is yet to be measured but will follow in a comprehensive evaluation process. The evaluation has begun by assessing the training program for its quality, knowledge transfer, and uptake.

## Conclusion

Youth-centred education and information tools supporting decisions and promoting knowledge sharing, shared decision-making, and facilitation of monitoring psychotropic medications are unavailable. A systematic and evidence-informed (i.e., explicit and tacit knowledge) process that includes youth and key stakeholder engagement with an active and iterative collaboration is required for successful development. This is especially true for groups such as youth with mental illness in which there is little to no representation of their preferences and values in the published literature.

## Acknowledgements/Conflict of Interest

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