Improving Drug Benefits for Children with Asthma: Results of a Multi-stakeholder Workshop to Build a Research Agenda

Amélioration des régimes d'assurance médicaments pour enfants atteints d'asthme : résultats d'un atelier multipartite pour définir un programme de recherche

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Abstract

Asthma is the most common chronic childhood disease, and evidence suggests that children underutilize inhaled corticosteroid ("controller") medications. Drug plans that provide benefits to children vary widely across Canada, and families may face high out-of-pocket costs. As an initial step in a knowledge exchange process aimed at motivating relevant research, a workshop was convened in March 2007 with diverse stakeholders to explore potential research topics within the theme of improving drug benefits for Canadian children with asthma. Six key challenges for further investigation were identified: (1) changing the perception of asthma from an episodic to a chronic disease, (2) improving diagnosis and management, (3) increasing intersectoral communication, (4) improving the quality of data, (5) developing better drug benefit plans and (6) practising more effective advocacy.

Résumé

L'asthme est la maladie chronique la plus répandue chez les enfants. Les données indiquent une sous-utilisation, chez les enfants, des médicaments corticostéroïdes inhalés (de « contrôle »). Les divers régimes d'assurance médicaments au Canada présentent une grande variété quant aux avantages pour les enfants. Dans certains cas, les familles doivent parfois débourser des sommes considérables. Afin d'entamer un processus d'échange de connaissances visant à stimuler une recherche pertinente, un atelier, qui a eu lieu en mars 2007, réunissait diverses parties prenantes qui ont réfléchi aux sujets de recherche potentiels touchant à l'amélioration des prestations pharmaceutiques pour les enfants canadiens atteints d'asthme. Six domaines de recherche principaux ont été cernés : (1) reconsidérer le statut de l'asthme pour en faire une maladie chronique au lieu d'épisodique, (2) optimiser le diagnostic et la gestion de la maladie, (3) améliorer les communications intersectorielles, (4) enrichir la qualité des données, (5) concevoir de meilleurs régimes d'assurance médicaments, et (6) effectuer une meilleure sensibilisation.

Paediatric asthma is the most common chronic disease of childhood. Prevalence and morbidity have increased over the past 30 years in Canada, the United States, the United Kingdom, Australia and New Zealand. Asthma affects between 10%–18% of Canadian children and varies by region (Millar and Hill 1998; Lava and Moore 1998). Proper management of asthma requires treatment with inhaled corticosteroid ("controller") medications, which have been reported to be underutilized by children (Rabe et al. 2004; Finkelstein et al. 2002). Asthmatic children also benefit from spacers for optimal inhaler use and peak flow meters for self-monitoring (Becker et al. 2005; GINA 2006), yet these devices are not typically covered by public drug plans (Ungar and Witkos 2005). Canadian children's access to asthma medications varies as a function of drug plan availability and medication costs (Health Canada 2000; Kozyrskyj et al. 2001; Ungar and Witkos 2005). Achieving optimal control is complicated by the fact that the drugs most needed for daily control of airway inflammation, inhaled corticosteroids, are among the most costly while "as needed" drugs, the short-acting beta2-agonists, are inexpensive with numerous generic equivalents available. In provinces such as Ontario, asthma medications and devices are not universally available to children through provincial plans.

High prices, insurance deductibles and high co-payments deter regular use of costly daily controller medications (Ungar et al. 2008). In most Maritime provinces, low-income families may face expenditures of up to 7% of household income to pay for one child's asthma medications, compared to 0% in Quebec, Alberta and the Yukon (Ungar and Witkos 2005). While Canada's National Pharmaceuticals Strategy looks at broad national issues including catastrophic drug coverage, the strategy does not focus on specific drug classes or highly prevalent conditions. No attention has been paid at the federal level to ensure provincial standards of benefits for vulnerable populations, such as children and low-income families.

The KT Initiative

Knowledge transfer (KT) is a multi-stage process that begins with articulating a health policy concern, in this case, improving benefits to Canadian children with asthma, identifying a range of interested stakeholders who share this concern and bringing these diverse stakeholders together in a forum that promotes an exchange of knowledge, experience and ideas. A KT initiative that brings diverse stakeholders together to inform a research agenda has been successfully implemented in the field of asthma and other therapeutic areas (Strunk et al. 2002; Masotti et al. 2007), to examine disparities in provision of health services to patients with asthma (Weiss 2007) and in prevention, diagnosis and treatment of cancer (Krieger et al. 2005), and to promote health safety (Health Canada 2006). The initiative described here includes these preliminary steps. Future stages will consist of systematically compiling available evidence

to support the pursuit of particular research questions that arise from the discussions, conducting relevant research and ultimately transferring research findings back to stakeholders, health practitioners and policy makers.

Professional groups and organizations having an interest in children and asthma were identified in various communities, including healthcare provision, healthcare decision-making and research. Leaders and those in senior positions were invited to participate in a workshop aimed at identifying research opportunities related to improving drug benefits for Canadian children with asthma. The workshop, held on the evening of March 27 and all day March 28, 2007 in Toronto, Ontario, brought together 30 participants including family doctors, allergic disease and respiratory paediatric specialists, pharmacists, health system administrators, provincial drug benefit policy makers, private drug benefit managers, patient representatives, asthma educators, patient and professional advocacy group representatives, parents, pharmaceutical policy experts, knowledge transfer experts, healthcare researchers and research trainees.

The primary objectives of the workshop were to (1) identify factors that affect children's access to asthma medications, devices and education and (2) identify and prioritize issues related to improving drug benefits for children with asthma that could inform future research. In addition, the workshop gave attendees an opportunity to learn about developments in asthma management from leading researchers; learn about provincial approaches to the provision of drug benefits to children across Canada; share cross-sectoral interests, challenges, experience and expertise in the management of paediatric asthma; identify future research needs and opportunities related to paediatric asthma health policy; and facilitate the development of a multisectoral, multidisciplinary, Canadian network of experts who share an interest in paediatric asthma health policy.

A context for small group discussions was set through a combination of expert presentations and interactive discussion. Presentations covered the significance of paediatric asthma as a health policy challenge (Dr. Wendy Ungar, University of Toronto/The Hospital for Sick Children); challenges facing researchers aiming to translate their findings into policy (Dr. Anita Kozyrskyj, University of Manitoba); strategies researchers can use to make a positive impact on policy decisions (Dr. Cameron Mustard, Institute for Work and Health); and an overview of recent research on childhood asthma control (Dr. Allan Becker, University of Manitoba). A multi-province panel discussion (Ontario, British Columbia, Manitoba and Quebec) compared provincial approaches to public drug benefit programs for children.

In the morning session, participants worked in three small groups to identify factors influencing children's ability to obtain access to the medications, devices and education they need for optimal asthma control related to (1) drug plan benefits and policies, (2) the provision of healthcare to children and (3) demographics, socio-economic status, family resources and parental health beliefs and behaviours. In the afternoon

session, the same groups convened to discuss and prioritize strategies that could be pursued by (1) private and public drug plan managers, (2) health professionals and (3) patient advocacy groups, parents, community agencies, schools and local governments.

Results of the KT Experience

Through analysis of the small- and large-group presentations and discussions, six overarching challenges were identified, which if addressed through research programs that generate evidence, would make a significant impact. These challenges and the specific points supporting them are described below.

Challenge #1: Change the perception of asthma

Asthma must be recognized and treated as a chronic disease. Three issues related to this challenge were identified:

- Asthma diagnosis is hard for parents and children to accept.
- Expectations of patients and their families regarding stigmatization must be anticipated.
- While the health system is well organized to provide acute care for children with asthma, it places less emphasis on long-term secondary prevention and management of asthma as a chronic disorder. A chronic disease management strategy for education and treatment is needed.

The perceptions of parents and the reluctance of some to accept their child's asthma as a condition requiring ongoing attention has been documented (Lauritzen 2004; Peterson-Sweeney et al. 2003). Education as well as enhanced communication between parent and provider can help improve parents' abilities to manage their child's condition (Kolbe 1999).

Challenge #2: Improve the diagnosis and management of paediatric asthma by healthcare providers

- Respiratory disease does not have a high profile among primary care practitioners.
- Better training and education about asthma as a chronic disease is needed among a wide range of healthcare professionals.
- Better assessment tools are needed for asthma diagnosis, especially in young children.
- Doctors are not paid to provide asthma education and may not perceive patient and family education as an essential component of asthma management.

- Access to primary care providers is restricted in urgent situations.
- Access to Certified Asthma Educators is limited.
- Continuity of care from setting to setting and from childhood to adulthood is inadequate.
- Healthcare practice would benefit from bottom-up pressure from parents to obtain the proper diagnosis and treatment for their children.
- Practitioners must consider socio-economic factors and families' financial resources in approaching asthma management and medication use.

While excellent clinical guidelines are available for the management of asthma by primary care providers (Becker et al. 2005), provider knowledge of and adherence to guidelines have been shown to remain issues (Chapman et al. 2001; Cloutier et al. 2006; Cabana et al. 2000). The guidelines are principally aimed at physicians, whereas asthma educators and pharmacists play critical roles in asthma management (McLean et al. 2003).

Challenge #3: Increase and improve intersectoral communication

- Regular networking is needed among healthcare providers, policy makers, researchers and parents.
- Asthma Action Plans are tools that a range of care providers can use to improve communication between health professionals and parents and their children.

Challenge #4: Improve the quality of data and evidence

- There is untapped potential to track and study prescription patterns (e.g., electronic prescriptions).
- Provincial ministries of health should consider the effects of drug-related benefits on the utilization of non-pharmaceutical health services.
- Means should be created within the health system to track asthma-related health resource use – hospitalization, drugs and physician services – and establish alerts where unnecessary services or expenses occur.
- Few employers track absenteeism. Data on absenteeism related to burden of caregiving attributable to paediatric asthma are needed.
- Drug manufacturers need to do more clinical trials of paediatric asthma medications with relevant comparators and consider safety, formulation, device and administration issues specific to children.

Challenge #5: Develop better drug benefit plans

- Listing decisions should be part of an asthma risk management strategy rather than based on the clinical benefit of individual drugs.
- There is a need for an education component in drug benefit plans.
- Payers and pharmacy benefits managers need to devise plans that include incentives for patients and caregivers to change behaviour and follow a chronic disease management strategy.
- Lack of generic drugs (e.g., for inhaled corticosteroids) is an issue in Canada; brand-name drugs are costly.
- Incentives should be created to allow more generics into the marketplace, especially for asthma drugs that combine multiple medications within a single inhaler device.
- Drug costs are a problem for the working poor and the not-so-poor with multiple asthmatic children.
- Many drug plans don't cover devices, e.g., spacers and peak-flow meters, which enhance delivery of medication and self-management (GINA 2006).

A trend has arisen in the United States and Canada to increase cost-sharing by subscribers as private and government drug plans raise deductibles and co-payments that families pay out of pocket (Tamblyn et al. 2001; Crown et al. 2004; Stevens et al. 2003). There has been very little scrutiny of the impact of these trends on health outcomes in children.

Challenge #6: Practise effective advocacy

- The image and understanding of asthma need to be re-profiled with patients, care providers and payers.
- Advocacy is needed to raise awareness and funding for asthma research, services and education.
- Susceptible, vulnerable subgroups of children with asthma may require a different advocacy focus.
- Health researchers must advocate for population-based databases of all prescriptions dispensed to children, linking private and public sector data.
- World Asthma Day and other high-profile events, such as charity walks or runs, can help create a wider awareness about asthma.
- The trajectory of health suggests that maintaining good health during childhood can lead to better health in adult years. This point should be stressed in advocacy efforts.

Lessons Learned

The process of selecting key individuals across a wide range of stakeholders who share a common health policy interest and bringing them together in a roundtable forum to share experience, knowledge and perceptions proved to be an extremely useful approach in motivating and informing a research agenda. Workshop participants identified a number of specific strategies that could be pursued to improve drug benefits for children with asthma.

Private and public drug plan managers could

1. assess and reduce inappropriate medication utilization;
2. integrate asthma education into drug plan benefits;
3. share and learn from experiences of plans in other jurisdictions; and
4. move forward on a national consensus regarding a Canada–wide drug plan design.

Health professionals could

1. develop a new chronic disease management model for paediatric asthma, emphasizing secondary prevention;
2. define and address the barriers to obtaining drug benefits; and
3. develop and implement behaviour change strategies for health professionals to improve practice.

Patient advocacy groups, parents, community agencies, schools and local governments could

1. promote asthma education programs;
2. promote use of technology in drug administration and adherence, self-efficacy, learning and communication;
3. develop intersectoral links;
4. improve asthma management in schools; and
5. stay informed regarding existing and planned initiatives in lung health and child health Canada–wide.

From an analysis of the discussion of the strategies, several research opportunities were revealed, including:

- comparisons of provincial initiatives and appraisals of the strengths and weaknesses of provincial drug benefit plans; comparisons of patient outcomes such as medication use and urgent health services use in provinces with special programs or policy changes to those in provinces without such initiatives;

- investigation of the phenomenon of private plans imitating public plans in a private/public mixed plan jurisdiction;
- an analysis of social, financial, cultural and other barriers to improving drug benefits for children with asthma across settings;
- documentation of paediatric asthma prescription and adherence patterns, the reasons for and opportunity costs of suboptimal paediatric asthma medication utilization and prescribing;
- evaluation of paediatric asthma diagnostic and control assessment tools for very young children;
- clinical trials of paediatric asthma medications with relevant comparators;
- studies of drug safety considerations specific to children, including pharmacogenomics;
- identification of incentives and behaviour change strategies that would motivate healthcare providers to (1) incorporate patient education at the point of care/dispensing, (2) adopt a chronic disease management approach that emphasizes secondary prevention and (3) improve the continuity of care;
- evaluations of mechanisms to integrate asthma education into drug benefit plans.

Next steps require assembling academic teams to consider each of the suggested research topics and conduct comprehensive and systematic reviews of the evidence. Workshop participants suggested that future research projects be pursued by academic teams in collaboration and/or consultation with primary care providers, paediatric specialists in respiratory and allergic disease, pharmacists, asthma educators, patient/parent representatives, policy makers, insurers and drug benefit managers (public and private), pharmaceutical company representatives, health system administrators and knowledge translation experts.

Conclusions and Implications

According to participants' evaluations, the workshop was successful in bringing together disparate groups of professionals and community members to focus on a particular public health issue in paediatrics. There was significant mutual learning and inspiration, and a collaborative tone was maintained throughout. In addition to suggesting research topics, participants provided a number of suggestions to promote the translation and uptake of future research findings. These included strengthening relationships between researchers and stakeholder organizations, facilitating patient-centred communication, increasing public awareness of asthma as a chronic disease and promoting secondary prevention and optimal management strategies.

Expected outcomes of this workshop include increased cross-sectoral networking and the identification of a broad, multisectoral research team to facilitate the development of high-impact, policy-relevant research that can be supported within the AllerGen research program, by the Canadian Institutes of Health Research (CIHR) and by other funding agencies. One of the enduring benefits of this event was setting a successful precedent for networking and relationship-building among diverse stakeholders and experts who share an interest in improving outcomes for children with asthma.

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