



**SHAPING THE RESEARCH/POLICY NEXUS**  
A Policy Workshop Sponsored by AllerGen, Program C  
February 18, 2009  
Fairmont Chateau Laurier, Ottawa, Ontario

This report captures the participants' insights and recommendations recorded during three table work sessions.

After each set of presentations from scientists or advocacy representatives, participants were asked the three following questions:

1. On the basis of what you have heard, what conclusions can you draw?
2. What suggestions do you have to advance the research agenda?
3. What steps can we take to build sustainable relationships between science, policy and advocacy?

Their contribution were captured on flip charts, and shared with all the workshop participants.

The report's structure follows the sequence of the questions asked.

**1. On the basis of what you have heard, what conclusions can you draw?**

**Policy development**

*Observations:*

- Policy happens in reaction to crises, which is not optimal.
- Policy is uncoordinated and incoherent
- Much fragmentation and variation among Provinces
- Policies are not evidence-based
- Emotions and perception of risk among stakeholders influence policy
- Disconnect between the needs and preferences of allergic children and across-the-board (e.g. policies such as a "peanut-ban")
- Policy at school-board level encounters resistance from teachers and misconceptions from the public

*Recommendations:*

- Include the perspective of all stakeholders so that they feel engaged in implementing policy; in proposing policies that address allergies and asthma; in seeing the relevance of data; and in easing the emotional burden of those suffering, their families and their friends

- Involve those who are formulating policy, and identify policy entrepreneurs (inside and outside of government)
- Identify policy champions for each stakeholder; and include children's voices
- Review the immunity clause with teachers and educators; and identify with them how policies play out
- Develop consensus-based documents until evidence becomes available
- Bring stakeholders together to define policy options
- Think of different ways to address questions: how to prevent exposure; what to do when exposure occurs; how to reduce parent and child anxiety

## **Legislation**

### *Observations:*

- Legislation is often required when there is a failure of policy
- Even with legislation, children and families do not feel safe
- The translation of legislation into a school environment poses a significant challenge

### *Recommendations:*

- What is really needed is an evidence-based policy without legislation

## **Language**

### *Observations:*

- Policy-makers and scientists do not speak the same language
- Knowledge is not translated and tailored to audiences

### *Recommendations:*

- We need a joint approach to spread the message across; and a coordinated communication process that includes:
  - The medical community, general practitioners, specialists and nurses
  - The Public Health community, so that we can communicate the big picture
  - Teachers and school leaders
  - Knowledge translators who will create a language bridge between scientists and policy-makers; ensure that the evidence from the research bench is communicated in terms the public can understand; and who will be able to properly tailor messages to various audiences

## **Advocacy**

### *Observations:*

- Advocacy groups play a key role in education, awareness, support and advocacy
- Current emphasis is on children
- While asthma is one of the most prevalent chronic conditions affecting Canadians, no crisis is perceived by the public. This is posing a challenge for asthma advocacy.
- Public awareness is still lacking; there are many misconceptions about food allergies; and there are unmanageable expectations from parents

*Recommendations:*

- Advocacy groups need the resources to train stakeholders in advocacy
- Consider an approach that empowers people and make them take personal responsibility for their health
- Advocate for improved health labeling
- Partner with and learn from “big diseases” advocacy organizations
- Consider involving the industry when developing advocacy strategies
- Approach government as a larger advocacy group, rather than as three separate organizations

## **2. What suggestions do you have to advance the research agenda?**

### ***Socio-economic agenda***

- Determine the costs and economic burden of allergic diseases in Canada
- Determine the consequences of misdiagnosis on society and on the quality of life of families
- While the emphasis is on children, we need to find out what happens to adults, what the life threatening factors are, and what are the consequences on stress and efficacy across the lifespan
- More research needs to be conducted on First Nations; including determining the impact of reimbursement of allergy and asthma medications
- More research needs to be conducted on low socio-economic status populations; we should involve researchers and clinicians who deal with low SES; as well as looking at differences between Canada and other countries

### ***Public Health Agenda***

- Research should focus on prevention to inform public health
- Find out what works and optimize the use of communication and education
- Investigate specific situations, such as diagnosis by naturopaths in British Columbia
- Impacts of allergy diagnosis on teenage eating habits
- What needs to happen so that the asthma Bill of Rights is widely implemented?
- Issues specific to First Nations need to be researched more deeply, as they face numerous barriers to properly manage asthma

### ***Measurement***

- Rethink key measurement questions: what are we measuring & does it help us evaluate policy?
- Identify relevant issues leading us toward change: what are the best surrogate measures?
- Meet the challenge of developing and tracking outcome measures (e.g. key measure: # of accidental exposures and how they are managed)
- We should study whether Sabrina’s law reduces the number of incidents, and whether this is handled correctly
- In the process of gathering data, think about its relevance to the stakeholder

- We need to do more qualitative and quantitative research on specific risk to exposure; how do we stratify risk? Is there a threshold?

### ***Research management***

- Need to make the stakeholders aware of how research works:
  - How is it organized?
  - How do scientists work together
  - How do they communicate research results
  - How is it different (or similar) to what is being done outside of Canada
- Develop better communication processes to bring all levels of research to policy & society
- Continue to talking with all stakeholders to find out what they wish to see on the research agenda

### ***The situation in schools***

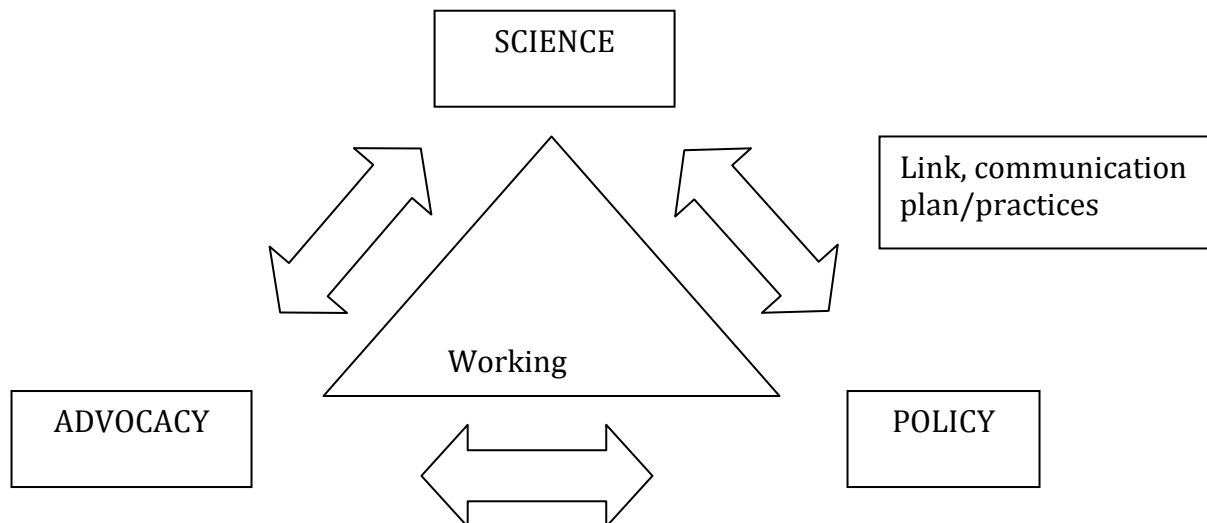
- Researchers need to work more closely with Public Health counselors
- Scientists need to play a role educating the educators
- Need to find out how various challenges play at school, e.g. hand washing practices, asthma management, and general allergies management
- Find out optimal roles for all partners: parents, policy makers, public health, and schools; clarify the scope of responsibilities and what boundaries exist
- The governments need to provide support for teachers, as families have changed
- Research the optimal use of the EpiPen; what processes and education must be in place? Can technology help, e.g. Redesign the EpiPen so that “it could talk”

## **3. What steps can we take to build sustainable relationships between science, policy and advocacy?**

### ***Framework for action***

- Building sustainable relationships between science, policy and advocacy requires mapping the three communities:
- Identify the membership in each of the communities
- Find out how they are organized, and operate
- Identify their responsibility in relation to asthma, food allergies and anaphylaxis
- Document how they are affected by legislation and data
- Then, pursue a plan of action:
  1. Identify who is the point person in each stakeholder group
  2. Determine points of overlap and common or shared responsibilities across communities and within, so that desired outcomes are identified
  3. Explore successful examples of relevant strategies, e.g. helmet law
  4. Create a framework with a defined strategy

## BUILDING SUSTAINABLE RELATIONSHIPS



- Building sustainable relationships also includes pro-active communication between communities, as well as persistence and consistency. It takes time to become a credible and trusted advisor. Strong personal relationships are essential.
- Such personal relationships will help each community to learn about the two others:
  - What their mission is
  - How they work
  - What are their reward systems (their motivators)
  - Key questions include: Tell me about your world? What do you want to achieve? What are your needs? How can we work together to help you?

### **Communication Tips**

- Be aware that decisions are made in committees, and sometimes behind the scenes
- Media can hijack the agenda
- When advocating, plan to meet all parties
- Cultivate regular on-going relationships
- Leverage not for profit agency contacts
- Make your message memorable, know your message, stay on message, and say it over and over again
- Seek to understand before being understood
- Put a human face on public health issues regarding asthma, allergies and anaphylaxis
- Develop culturally appropriate materials to ensure inclusion of target populations such as first nations
- Include economic impact whenever feasible; be aware of health economics

### ***Building blocks***

- It would be very helpful to synthesize research, and learn from researchers involved with policy workers
- Such a synthesis would help create a consistent message across all areas
- We need research on the most effective mechanisms that make communication effective
- Science and Advocacy need to understand “what is policy?”
- While industry does not seem to fit within the science-policy-advocacy nexus, it plays a key role in influencing policy, science and advocacy
- Each community should seek partnerships beyond their boundaries, e.g. National Aboriginal Nurses Association and First Nations and Inuit Health Branch