Toward NFASt: Poster (EAACI 2017 Congress)

On July 11, 2017, NFASt co-leader Dr. Susan Elliott presented the poster "Toward a National Food Allergy Strategy for Canada" at the European Academy of Allergy and Clinical Immunology (EAACI) 2017 Congress in Helsinki, Finland.

A lightly edited transcript of her presentation follows.

My name is Susan Elliott and I'm a medical geographer from the University of Waterloo in Canada. If you've never heard of the University of Waterloo before, we're the ones who invented the Blackberry. That's what we're most famous for—other than medical geography.

I'm here with two of my colleagues from the AllerGen Network, a Networks of Centres of Excellence: Diana Royce, the Managing Director, and Judah Denburg, the Scientific Director.

Networks of Centres of Excellence

The Networks of Centres of Excellence program in Canada has a very different way of funding research. It's different for three unique reasons.

First, the NCE program provides funding for a long period; in our case, 14 years. That's a long time—longer than most other grants, and that means you can really build relationships and build on what you're doing in your science and do it well.

Second, it is unique that to secure the funding, you must have all three types of sciences and scientists in your network. You must have basic and clinical scientists; you must have natural scientists; and you must have health and social scientists. In the beginning, including this requirement was a way to force people to work together to create transdisciplinary research. Now that we've been working together for almost 12 years, we all like each other and we're all good friends; we respect each other and we do good transdisciplinary research.

Third, what's unique about the Network of Centres of Excellence context is its strong focus on knowledge translation. We don't just do excellent science; we're supposed to apply that science. It's supposed to have impact. As the former president of the NCEs once said to us, "We don't fund research; we don't fund researchers. We fund impacts on the lives of Canadians."

The Allergy, Genes and Environment Network (AllerGen NCE)

This (Fig.1) is what the AllerGen Network's research strategy looks like. It's not what it looked like in the beginning. In the beginning, we had a whole bunch of different projects all focused on allergies and asthma. In fact, I think we had over 70 projects.

As we matured and evolved over time, we consolidated into three fundamental themes which have evolved even further into three Legacy Projects. Our funding will end in 2019 and we will not be funded again, but we want to leave a legacy out of all this fantastic science.

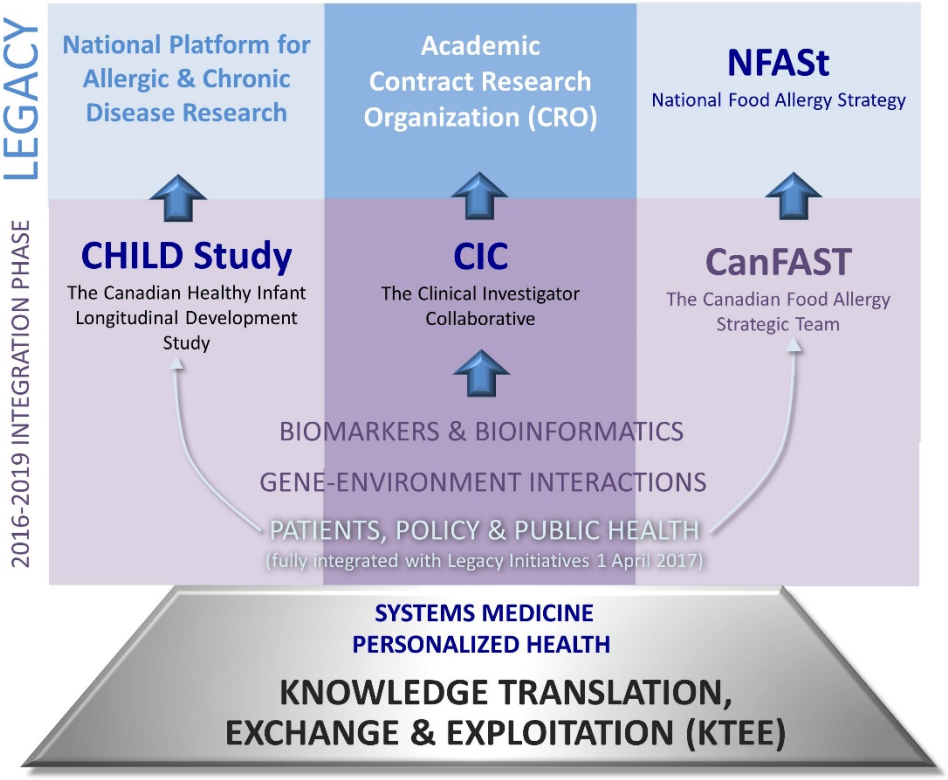

Figure 1: AllerGen's integrated research strategy

The first Legacy Project is what's called the CHILD Study. It's a birth cohort that seeks to understand the causes and consequences of allergies and asthma. Three thousand and five hundred children are currently enrolled in this birth cohort and it's quite spectacular. The second is the Clinical Investigator Collaborative that focuses on diagnostics and the development of therapies for asthma. The third is a substantial food allergy research theme: CanFAST, or the Canadian Food Allergy Strategic Team, which we now see emerging as a National Food Allergy Strategy for Canada.

Towards a National Food Allergy Strategy (NFASt) for Canada

Through CanFAST and the other aspects of AllerGen's work, we know a lot about food allergies.

What We Do Know

1. We know in Canada, for example, that we have a prevalence rate of 7.5%. We didn't know that before we started. In Canada, we didn't have any prevalence data; we always referred to the US or to the UK data. We didn't have our own. Now we do.
2. We also know that 50% of Canadian households are affected by food allergy, directly or indirectly. I may not have an allergy and my child may not, but I have to prepare lunches for my child to take to school and there's a nut ban at the school, or I have visitors with food allergies coming to my house—so half of Canadian households' report being affected directly or indirectly.
3. We know what the top 10 food allergens affecting Canadian children and adults are.
4. We know how food allergies are experienced among school children and vulnerable populations, because we conducted not just large epidemiological surveys—we also conducted very intensive, qualitative follow-up studies with the most vulnerable and the most affected. We followed up by doing in-depth interviews with low-income families: How do you cope in a food allergy when you're relying on a food bank? We in Canada are also a nation of immigrants. We have a lot of new Canadians among whom there are huge health literacy issues, so we followed up with new Canadians, for example, from Asia, for whom "anaphylaxis" doesn't exist in their native language. That's a huge health literacy issue in terms of knowledge dissemination.
5. We know anaphylaxis rates have doubled in Canadian children from 2011 to 2015.
6. We know from recent studies that early food introduction is best.

But there's a lot that we don't know.

What We Don't Know

1. We don't know if food allergy is increasing in Canada. We don't have good data. We will by August 2017, because we just got out of the field with our third national survey.
2. We don't know the economic cost of food allergy, so it's hard to convince policymakers to make policy.

3. We don’t know the impact of the common use of “may contain” precautionary allergen warnings on food, though we do know it’s a huge problem for affected individuals.
4. We have big questions around legal and human rights. In the province that I live in, Ontario, in Canada, there have been three human rights challenges from parents who don’t feel that their children are being dealt with appropriately in schools, despite their food allergies. They’re going right to the Human Rights Commission.
5. What are the experiences of university/college students with food allergies? We know from our research participants that in elementary school, they’re very well protected; in high school, much less so. Once they get to university, early studies of ours say: “we feel like we’re on our own and nobody’s looking after us.” In 2015, a first-year university student at one of the top universities in the country, on her third week of school, died in the cafeteria because of a cross-contamination issue.

So, there’s lots we know and lots we don’t know.

NFASt Objectives

What are the objectives of a National Food Allergy Strategy for Canada?

We want to determine whether prevalence is increasing. We want to know something about economic cost. We want to develop an evidence-based national approach to food allergen management. We want to be able to provide legal opinions on whether food allergy is a disability, and we want to reach out to that University/College cohort, because as children grow up and move through that cohort, and move into the workforce, they’re going to have social, economic and political power, and how are we going to deal with that from a policy perspective?

NFASt Methods

How are we going to do all this?

We have a four-prong strategy.

1. We’re going to learn from others. Australia has already done this; they’re the first off the mark. What have they done and what can we take from their experience? We have a national stroke strategy in Canada—a very different health outcome, but what can we learn from that program?
2. We’re going to continue to mobilize the knowledge created within our Canadian Food Allergy Strategic Team and other parts of AllerGen, like our birth cohort.
3. We’re going to begin to fill the existing gaps with the creation of new knowledge. We don’t know everything and we need more research.
4. We’re going to create some new dissemination tools to get the message out. We can’t do this alone as scientists; we need to have those patient groups on our

side. I had a meeting this morning, very early, with patient groups here at the EAACI who came from all over the world to be here to learn about what is the cutting-edge science. We need to also learn from them. What are the questions that you need answered? What information do you need, and in what form do you need that? How can we work together to translate that knowledge to change policy, to change practice, and change quality of life?

NFASt Partners

These are the partners that we're working with:

- Allergic Living
- Allergy Asthma Information Association
- Anaphylaxis Canada
- Association Québécoise des Allergies Alimentaires
- Asthma Society of Canada
- Canadian Institute for Health Information
- Canadian Society of Allergy and Clinical Immunology
- Food Allergy Canada
- Health Canada
- The Sandbox Project

NFASt Projects

We now have a number of projects underway to start moving along this continuum. We have some research projects and some knowledge dissemination projects. We are exploring rising prevalence. We are looking at the economic cost of food allergy. We're looking at food allergen management in the Canadian context and we're looking at the post-secondary experience. We also have a series of White Papers being written to try and influence policy. "Is food allergy a disability?" is one of the first White Papers were producing. We're developing expert guidelines on managing food allergies in schools, looking at the issue of food allergies as a human rights issue, and then developing new knowledge dissemination tools, like "making sense of allergies in the Canadian context." There's a wonderful UK document and we're going to produce a Canadian version.

Conclusions

Do we have all the answers? No, if we did we wouldn't have 8,000 people at this conference talking about the causes and consequences of allergies.

Do we have to wait until we have all the information? No.

Do we have enough information to start making good, strong policy choices? I think: yes. In the context of tobacco and lung cancer, for example, it was 1964 when the US Surgeon General said: "There's a relationship between lung cancer and cigarette smoking or tobacco consumption; we're going to start making huge public health

policies around this," but it was 30 years later before we knew the biological mechanism. We don't have to wait until we have all the answers to make good, strong policy choices.

We have a lot of priorities—no, we can't do them all, and that's why we focused on the ones I've shared with you.

We're going to keep our stakeholders meaningfully involved at every stage of what we do.

We're going to develop a prototype for Canada that we hope will have relevance for other countries and can be shared globally. Thank you.