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***From cell to society and back again: A Summary of the  
AllerGen NCE Inc. Social Sciences Visioning Workshop***

King City, ON,  
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Innovation from cell to society  
[www.allergen-nce.ca](http://www.allergen-nce.ca)

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## 1.0 Executive Summary

AllerGen NCE Inc. (AllerGen) held a Social Sciences Visioning Workshop December 1<sup>st</sup> and 2<sup>nd</sup>, 2005 at Eaton Hall in King City, ON. Over two days, 17 leading social science researchers from across the country, along with several AllerGen theme leaders, discussed the potential for synergy between activities within the AllerGen NCE and the social sciences research community in Canada and beyond.

Workshop participants concluded that social science questions that promote the achievement of AllerGen's mission emerge from all five Themes / Programs of research currently identified. The social scientists' approach to address allergic and immune disease research through a social science "lens" differs from the approaches currently used by researchers within the Network.

AllerGen's research program is currently oriented from "cell to society". However, the social scientists' questioned whether or not AllerGen should or can **also** look at allergic and immune diseases from "society to cell". That is, focusing the "lens" on societal impacts of a variety of social scales. In so doing, AllerGen needs to look at macro-level populations and policies to balance the existing focus on cell research and to question the existing conceptual framework for relevance to the socio-behavioral and societal aspects of AllerGen's mission.

AllerGen's research program must inform industry *vis-a-vis* the economic, cultural, social and political inputs of allergy and related research or else a major opportunity will be missed. The challenge is that the social scientists participating in the AllerGen Network must be realistic about engaging in an NCE, which requires open, two-way dialogue across disciplines and sectors. There is an opportunity for Social Scientists to engage with industry but AllerGen must facilitate the integration of Social Scientists into the Network and create and support opportunities for their involvement across the entire program of research.

Social Science research opportunities generated at the workshop include:

- The role of the socio-economic environment
- The impacts of differing spatial and social scales
- Individual choice and behavior
- Public policy, inputs and outputs
- Knowledge translation
- Secondary data analysis
- Legal and ethical issues
- The role of culture
- Ethnicity and immigration
- Special populations

This is by no means an exhaustive list of topics discussed at Eaton Hall; many seeds were planted and will continue to sprout and bear fruit over the life of the Network.

In terms of involving Social Science community researchers in the Network, the following strategies were recommended:

- Targeted LOIs.
- Strongly encourage currently funded Principal Investigators, who want to apply for second year funding, to expand their scope of work to include an aspect of the social sciences in their project.
- Recruit specific individuals to join existing programs of research to answer related social science questions as part of an interdisciplinary / multi-disciplinary team.
- Find ways to continue the dialogue.

## **2.0 Introduction**

AllerGen NCE Inc. (AllerGen) held a Social Sciences Visioning Workshop December 1<sup>st</sup> and 2<sup>nd</sup>, 2005 at Eaton Hall in King City, ON. Over two days, 17 leading social sciences researchers from across Canada, as well as several AllerGen theme leaders, discussed how AllerGen's research agenda could more fully integrate social science research and social science researchers into the Network to help AllerGen achieve its goals of contributing social and economic benefits to Canada.

To set the stage for the next day's discussions, Dr. Judah Denburg, the Scientific Director and CEO, provided an overview of AllerGen's vision, mission, mandate and current research investments. To familiarize the group with Network activities to date, Network theme leaders Dr. Malcolm Sears and Dr. Dean Befus provided detailed overviews of Theme II: Environments, Populations and Society and Theme III: Mechanisms and Biomarkers. Ms. Lori Sheremeta, Research Associate, University of Alberta and Ms. Nola Ries, Research Associate, University of Victoria provided an overview of the emerging legal and ethical challenges in health and biomedical research more generally. On the morning of December 2, 2005, AllerGen Research Management Committee member, Dr. Susan Elliott, provided an overview of Theme V: Prevention, Control and Public Policy (on behalf of Dr Cam Mustard).

Please see Appendix A for a complete participants list.

## **3.0 Potential Synergies**

Participants saw synergies between social science research and the goals and objectives of AllerGen. These are steeped in the traditions and approaches of social scientists who view the world through a different lens than their natural science counterparts. Herein, health is a socially constructed concept. As such, social scientists may be interested in investigating:

- How individuals construct their allergic environment
- The commercialization of allergy as a disease
- The social determinants of allergy and asthma
  - The role of the socio-economic environment
- Rural and aboriginal health promotion, resources and environmental issues
- Analysis of secondary data sets through a social sciences lens
- Role of individual choices, action, cultural and cognitive aspects of living with allergy and asthma
- Social support networks and social capital as determinants of health
- The societal impacts of the science of genotyping, including ethical and legal implications/issues.
- Public and health policy

- Asthma and anaphylaxis in schools and other institutional settings
- Social networks of youth in school and society,
- Youth interface and behavior in the context of the social construction and definition of disease
- Examination of the role of NCEs in Canada regarding commercialization and impact on the research community
- Bio-banking and ethics
- Up-take of the prevention message
- Health outcomes in the workplace
- Technology, innovation, economic constraint, tensions re: resource allocation, policies act as barriers to access, barriers posed by pharma-care etc.
- If we have a better pharmacogenic understanding, who pays for new drug treatment?
- Interaction between socio-economic status and health outcomes, asthma control
- Geographic patterns of allergy and asthma outcomes
- Population health and health behaviors.

AllerGen is well placed to serve as the platform for creating the transdisciplinary synergies that will allow us to begin to work together in interdisciplinary teams in order to answer these very complex research questions.

#### **4.0 Gaps:**

Participants were asked to note any perceived gaps in AllerGen's research platform.

Gaps identified, from the perspective of social science researchers, included:

- Social process issues; for example the coercive power of the social over individual decisions and experiences
- Psychology, neuro-psychology, stress from a human sciences perspective
- Domestic workplace issues
- Cognitive anthropology; culture and mental pathways, understanding how people understand problems
- Climate change
- Economic burden of care
- Affordability of lifestyle changes (i.e. changing jobs due to allergen presence)
- History of listing allergy and asthma medication for public insurance linked to public policy
- Changes in policy environment

- Prescription v.s. over the counter
- Voices of vulnerable populations, children, aboriginals
- Genes studied over time and in particular spaces (mathematically = genes x time x space)
- Urban vs. rural issues
- Immigration, migration, ethnicity.

#### **4.1 The Social Scale was identified as an area which represented a major gap**

##### **Elements discussed included:**

- Individual, personal risk
- Social constructions of health and illness
- Social support and stigma (related to disease or illness)
- Family and broader social networks
- Settings: school, workplace
- Societal level, public policy, health promotion, prevention, control
- Environmental exposures and control
- Political economy of health and health care
- Social scales are nested within each other and interactive
- Find routes of entry that define operational research design
- Social linguistics play a role in allergy
- The voice of the allergic needs to be involved in setting AllerGen's research agenda
- Communications research - how to best communicate with all stakeholders involved

#### **4.2 Links from AllerGen's current research program to Social Science research opportunities**

##### **Theme II – Environments, Population and Society**

- What is the difference between having asthma and having occupational asthma?
- Exposure approach, outcomes on population sub-groups
- Exposure response assumes we have enough biological evidence to define higher or lower risk environments

- Outcomes – are there populations or environments with higher incident rates? Those should be studied.
- If exposure – outcome relationship is known, then you can study impact on sub-groups
- How to explore the geography of responses, spatial scale?
- HOW TO TAKE ADVANTAGE OF EXISTING EVIDENCE?
- Theme II – questions about social construction of illness and disease management
- How do families deal with illness, the insurance system?
- Social capital and how do people network to handle health problems?
- Secondary data analysis
- Immigration data and population growth
- Economic growth
- Environmental health studies on development in-utero exposures and the impact of the next generation, not just current child.

**Social science has an essential role to play in all themes.**

Birth cohort – what are the social science questions?

- How are the mothers chosen?
- Include a range of socio-economic status.
- What are the most important social determinants?
- Can you over-sample existing data collection efforts?
- Rural and aboriginal population?
- Should sample be random or focused?
- Should cohort be setting based?
- Include a range of ethnicity.

## 5.0 Group Development of Driving Questions

It was agreed that AllerGen required “**driving questions**” that focused the Network on unifying themes and focused outcomes. Participants suggested the items below as considerations in the development of “driving questions”. These suggestions also illustrate how social science research could contribute to answering such questions.

### 5.1 Explain the apparent increase in allergy rates.

- Environmental explanation - what has changed in terms of exposures?
- What are the intervening variables between environment and response; are people changing biologically or genetically?
- Are there social factors that have changed, has the population mix created an increase in susceptibility, have there been changes in diet or other behaviours?
- Have the definitions of illness or disease changed?
- What are the determinants of self-reporting and how have they changed?
- How have the objective rates of allergy changed compared to self-report rates?
- What is the perception of risk related to exposure?
- Define what allergy means in different settings
- Understanding the social construction of illness.

### 5.2 Gene – Environment Interaction

Factors:

- Lifestyle change
- Population movements around globe (immigrant populations, urban, rural, domestic shifts in population dynamics)
- Behavioral changes
- Natural laboratories
- Look at outcomes e.g. comparisons between East and West Germany
- Hygiene hypothesis
- Immune cognitive deficiency
- Allergy is childhood focused and leads to questions about:
  - What is the appropriate form of treatment of allergy?
  - What is the definition of childhood?
  - How do you handle the experience of disease in children?
- What is the degree to which allergy as a disease is socially constructed (compare to fetal alcohol syndrome)?
- When labeled “allergic” what does that mean to your life?
- Is allergy correlated with other related diseases?
- Is it an illness that is defined spatially and by setting as well as clinically?
- What is the meaning of healing and wellness?
- Role of networks?
- Genetics: has the use of genetic tests changed behaviour?
- Use of different types of knowledge and technology in the health system
- Management of knowledge

- What are the links between allergy and obesity?
  - Impact of environments?
  - Genetic predispositions?
- Are there other auto immune diseases linked to allergy?

### **5.3. Environment**

Factors:

- Environment has changed dramatically
- New chemicals, flame retardants, GMO foods
- New chemicals exist
- Environmental factors are co-factors
- Exposure may have an indirect effect that compounds reactions to something else.

### **5.4. Maternal Health**

Factors:

- What are the pre-natal or post-natal social factors affecting maternal health that have no impact on the development of allergy and asthma on the first five years of life?
- Do data show rate increase that is prominent among children?

### **5.5. Genetics**

Factors:

- Genetics may be a promoter
- Important to look at the enablers
- Behavioral – lifestyle factors that turn on promoters
  - Diet, exercise patterns
  - Time spent indoors/outdoors
  - GMO foods
  - New chemicals
  - Stress
  - Home settings
  - Medication use
  - Cumulative causation
- Is there a tipping point?
- Lifestyle-environment-gene perspective
- Social science looks at the proportional weighting
- Should not isolate the question in the context of mother and child.

## **6.0 Methodology**

Social scientists bring a suite of methodological approaches that differ from those of the natural or clinical sciences. Essentially, this is because social scientists are attempting to answer very different questions and, ultimately, the question will determine the method. Typically, social scientists do not look for causal explanations in response to

the question ‘why?’ Rather, they examine levels of association and explore the “how” questions which provide an interpretive understanding. Qualitative research often looks specifically at outliers, as opposed to focusing on trends. Social science researchers’ interests lay in process questions and understanding the “so what” factor.

## **6.1 Evaluation**

In evaluating a social science focused LOI, it was recommended by participants that criteria differ from bio-medical research criteria.

- Types of partners will be different
- Networking responses will be different as the social scientists are not yet tied into the AllerGen network
- Dissemination strategies are different (book vs. paper)
- Knowledge mobilization (application of findings) is important for Social Science outcomes
- Personal data ownership is an issue in the Social Sciences – sharing databases Network-wide would need to be negotiated
- Natural alignment of the social scientist is with community groups and NGO’s
- In-kind contributions
- AllerGen’s international scientific advisory committee should contain social science expertise that Network researchers and new applicants would recognize as leaders in a social science research field

## **6.2 Social Scientists and the NCE**

It was noted by participants that it is important that AllerGen ensure social scientists understand the mandate of an NCE. There are terms and conditions of engagement with respect to NCE involvement that are different from investigator-driven research activity. Team grants are the approach of the future in medical/health research, but it is important to note that this way of doing business has not typically been a core part of the social sciences culture. As a result, it will be important to network and build bridges in ways that highlight the benefits of the NCE to all stakeholders.

## **6.3 Reaching the Social Science Community**

Participants recommended a number of routes and strategies by which AllerGen could effectively reach the Canadian social science research community. These include:

- Accessing the VPs Research at Canadian universities
- Annual meeting of the Social Science Congress
- SSHRC
- Canadian Bioethics Society

- Law Institutes at Universities
- Health Law Institutes
- Centre for Applied Ethics, University of British Columbia
- John Dossiter Health Ethics Centre, University of Alberta
- Centre for Health Services and Policy Research (CHSPR), University of British Columbia
- Centre for Health Economics and Policy Analysis (CHEPA), McMaster University
- CIHR Institutes (particularly population and public health; gender; aboriginal health)
- Provincial Genome Groups and Genome Canada
- Canadian Health Services Research Foundation (CHSRF)
- Knowledge Transfer Networks
- Centres for Health Promotion
- Non-Governmental Organizations
- Lung Associations
- Certified Asthma Education – Canadian Nursing Advisory Committee (CNAC)
- Occupational Health and Safety Agency for Health Care in British Columbia (OHSAH)
- Canadian Association of Geographers
- Canada Research Chairs
- NSERC, CIHR
- The academic associations of political scientists, economists, and other core social scientists.

#### **6.4 LOI Development**

In developing a social science LOI, participants recommended the development of a broad “goal statement” within which targeted social science questions could be posed. Examples are provided below:

**Goal statement:** Improving the quality of life for individuals suffering from asthma and allergic disease

- Examination of social sciences across the themes of the research program
- Birth cohort provides an opportunity to address a range of questions
- Focus social sciences on existing data sets, data mining
- Themes to be reframed to be inclusive of the social sciences
- Call to vet topic before full application, for instance submit a 400 work summation of the proposal for consideration/direction.

#### **Keywords:**

- Chronic disease orientation
- Socio-economic impact
- Social construction
- Health, illness, wellness
- How to manage chronic disease formally and informally as
  - A family

- An individual
- A workplace
- A school
- A pre-school or daycare
- What are the social processes and dynamics such as lifestyle, law, policy and health economics?
- Ethical, legal and social issues
- Cultural values/cultural models
- Risk perception, management and communication
- Equity, equality and social justice
- Health promotion and healthy public policy
- Aboriginal – “traditional ecological knowledge“ (TEK) in, health, traditional practices and patterns
- Geographic Information Systems (GIS)
- Spatial analysis

## **6.5 Strategy and Process**

It was recommended by participants that AllerGen proactively link social science and AllerGen researchers together and communicate the grid for assessment and weighting of research proposals in advance. A joint call between AllerGen and SSHRC could result in AllerGen leveraging additional funding in research areas of priority to its agenda.

1. Call for expressions of interest to those willing to network (400 words)
2. Phase II workshop to link and network people
  - Explain AllerGen NCE Inc.
  - Explain network governance and expectations
  - Facilitate Social Sciences researchers forming partnerships

## **7.0 Proposed Research Questions:**

At the conclusion of the meeting, workshop participants were asked to recommend a social science research question that would be consistent with AllerGen’s mission and goals. Research questions recommended include:

1. How is the quality of life understood in the context of Allergy and Asthma (in a clinical and/or societal context)?
2. Can AllerGen develop effective, evidence-based health promotion resources for those with allergic disease that can be incorporated into the health care system in a sustainable manner?
3. Defining allergies/asthma in different settings/places/populations.

4. What are the environmental (social/cultural) processes/correlates of allergies and asthma?
5. How are life-style factors (especially diet and exercise), related to self-reported allergy outcomes and diagnosed allergy conditions?
6. What is the distribution of the burden of illness across social class, gender, and health care providers?
7. What does “occupational” added to the diagnostic label i.e.: “asthma” vs. “occupational asthma” mean? Explore with social science.
8. The role of social capital.
9. Understanding why prevention doesn’t work (in the workplace context), complex relationships between the workers – employer – health care provider – insurers.
10. Is there a role for “healing” in occupational related disease?
11. Understanding barriers to care and health services - How do families with children with asthma cope?
12. A child’s health depends on a parent to act as gatekeeper to the health care system, and also as a proxy health reporter with respect to measuring outcomes. What is the meaning and value of parent as a proxy with respect to representing a child’s perceptions, a child’s needs and a child’s responses? Exploration of the convergence and divergence of parent and child perceptions of illness, such as asthma.
13. What are the healthy public policies needed to create conditions to decrease incidence of allergy and mitigate the impact of allergy on the lives of affected individuals (in occupational and educational settings)?
14. What are the short/medium/long term expectations with respect to commercialization? What are the legal and regulatory hurdles that must be met? What can be done prospectively to ensure the most efficient commercial path?
15. What sociological factors impact the gene - environment interactions that provoke the development of allergy in the young child?
16. This RFA is targeted at identifying the social determinants that would be important in the early development of allergy and asthma.
17. What social factors in maternal health and well-being would be important in the development of allergic disease?

18. What social-economic factors influence the development and management of allergic diseases early in life?
19. The cause of allergies seems to be an underpinning issue with many questions. The state of current literature may be an ideal starting point to prioritize the research questions. Letter of Intent (expression) for knowledge synthesis. A workshop could be organized from these results.
20. What are the population specific and spatial patterns of allergy and asthma specific outcomes? What are the socioeconomic, environmental, health service etc. factors associated with these patterns? Why?
21. Why are the rates of asthma and allergy increasing? Where and why are there heterogeneities? (across gender, ethnicity) How? What are the mechanisms re: (social) determinants and outcomes? So what?
22. What are the research questions that can be addressed at the social sciences levels using knowledge at the genetic level of asthma and allergy research
23. How are social processes and environmental conditions in combination with lifestyle behaviors and cultural values shaping the incidence of allergies, and the medical and social responses to them in Canadian society?

Research process questions proposed included:

24. How can we effectively incorporate the user community into AllerGen planning and research processes to generate the most valuable outcomes?
25. How can we influence policy, behavior, health promotion with all that we've learned?

## **8.0 Conclusions**

Overall, it was made clear by participants that social science questions that promote the achievement of AllerGen's mission arise across all five Themes / Programs of research currently identified. The social scientists' approach to addressing allergic and immune disease research from a social science "lens" differs from the approaches currently used within the Network's research program. AllerGen's research program is currently oriented from "cell to society." However, the social scientists' questioned whether or not AllerGen should or can **also** look at allergic and immune diseases from "society to cell."

It is important for AllerGen to look at macro-level populations and policies to balance the existing focus on cell research and to question the existing conceptual framework for relevance to the socio-behavioral and societal aspect of AllerGen's mission.

If AllerGen's research program does not inform the political economy of allergy for industry, an opportunity will be missed. The challenge is for Social Scientists participating in the AllerGen network to be realistic about engaging in an NCE and in open, two-way dialogue with a range of researchers across disciplines in order to build collaborations across the AllerGen research program. There are opportunities for Social Scientists to engage with industry, but AllerGen must facilitate Social Scientists' integration into the Network and create and support opportunities for their involvement and integration across the entire program of research.

Appendix A:

**Contact Information**  
Social Science Research Visioning Workshop  
Eaton Hall - December 1-2, 2005

**Contact Information**  
Social Science Research Visioning Workshop

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