Goals, Objectives, and Accomplishments

Melinda C. Aldrich, MPH, PhD
IJPC-SE, Board Member (ACE Representative)
American College of Epidemiology Annual Meeting
September 25, 2017
IJPC-SE

• Volunteer-driven, not-for-profit consortium of epidemiology societies and associations

• Impartially generate, report, and apply epidemiologic methods to the formulation, implementation, and evaluation of evidence for use in informing health policy
Historical Timeline of IJPC-SE

- **2006**: Founded
- **2008**: Operational policies formalized, Bylaws, EC leadership expansion
- **2010**: Asbestos position statement
- **2011**: Non-profit 501(c)3
- **2012**: International expansion
- **2014**: Development committee
- **2015**: Operational policies formalized, Bylaws, EC leadership expansion
- **2016**: Asbestos position statement
- **2017**: Non-profit 501(c)3

**Leadership**

- Roberta Ness, MD, MPH
- Susan Sacks, PhD
- Stanley H. Weiss, MD
- Colin L Soskolne, PhD
- Wael Al-Delaimy, MD, PhD
22 Participating National & International Societies, Associations or Epidemiology Sections
Infrastructure of IJPC-SE

Executive Committee:
N=5 members

Board Members:
N=\sim 2 representatives from each society/association

Interested Parties
Invited Guests
Expert Advisors:
N=18
Role of American College of Epidemiology

• ACE has been crucial in establishment of the IJPC-SE
  • Official mailing address
  • Engagement throughout
To ensure health for all through ethical, independent, and transparent science
Goal

• Serve the public interest by informing health policy and related areas through its work at the nexus of research and policy
Vision

• We strive to bring clarity to the science of epidemiology, paving the way to rational evidence-based policy. We work to promote and protect public health by serving as an ethical and effective counterweight to the misuse of epidemiology
Objective

• Coordinate inter-professional society activities that are related to research and practice in the generation of evidence, as well as in evidence-based policy application, formulation, implementation and evaluation

• Promote epidemiologic best practices to inform policy
Accomplishments

• Key infrastructure developed:
  • Bylaws
  • Policies relating to fundraising (used by member organizations)
  • Website with Member Archive
  • Donor Portal to raise funds
Accomplishments

• Develop Position Statements and Policy Briefs

• Board Members confer with peers within their societies, bringing exceptional broad range of expertise to discussion and review

• Each individual society follows own internal rules in determining whether it wishes to be a formal signatory when a project or paper approaches completion
Accomplishments

• Processes tend to take considerable time

• IJPC-SE is primarily geared to take on longer-term (vs acute) issues

• Allows rapid communication to highest levels of its member societies, particularly with emerging issues, enabling societies to react individually if appropriate
Influence of the HIPAA Privacy Rule on Health Research

Roberta B. Ness, MD, MPH
for the Joint Policy Committee, Societies of Epidemiology

Context Anecdotal reports suggest that the Health Insurance Portability and Accountability Act Privacy Rule (HIPAA Privacy Rule) may be affecting health research in the United States.

Objective To survey epidemiologists about their experiences with the HIPAA Privacy Rule.

Design, Setting, and Participants Thirteen societies of epidemiology distributed a national Web-based survey; 2805 respondents accessed the survey Web site and 1527 eligible professionals anonymously answered questions.

Main Outcome Measures Responses related influences such as research delays and added cost after Privacy Rule implementation, frequency and type of Privacy Rule-related institutional review board modifications, level of difficulty obtaining deidentified data and waivers, experiences with multisite studies, and perceived participant privacy benefits under the rule. Respondents ranked their perceptions of Privacy Rule influence on 5-point Likert scales.

Results A total of 875 (67.8%) respondents reported that the HIPAA Privacy Rule has made research more difficult at a level of 4 to 5 on a Likert scale, in which 5 indicates a great deal of added cost and time to study completion. A total of 684 (52.1%)
The Future of Epidemiology

Roberta B. Ness, MD, MPH, Elizabeth B. Andrews, PhD, MPH,
James A. Gaudino, Jr., MD, MPH, MS, Anne B. Newman, MD, MPH,
Colin L. Soskolne, PhD, Til Stürmer, MD, MPH, Daniel E. Wartenberg, PhD,
and Stanley H. Weiss, MD

Abstract

In this article, the authors discuss current challenges and opportunities in epidemiology that will affect the field’s future. Epidemiology is commonly considered the methodologic backbone for the fields of public health and outcomes research because its practitioners describe patterns of disease occurrence, identify risk factors and etiologic determinants, and demonstrate the usefulness of interventions. Like most aspects of science, epidemiology is in rapid flux. Several factors that are influencing and will continue to influence epidemiology and the health of the public include factors fundamental to framing the discipline of epidemiology (i.e., its means of communication, its methodologies, its access to data, its values, its population perspective), factors relating to scientific advances (e.g., genomics, comparative effectiveness in therapeutics), and factors shaping human health (e.g., increasing globalism, the environment, disease and lifestyle, demographics, infectious disease).

Asbestos Position Statement

Position Statement on Asbestos

from the

Joint Policy Committee

of the

Societies of Epidemiology (JPC-SE)

June 4, 2012

The Joint Policy Committee (JPC) of the Societies of Epidemiology (SE) is a consortium of epidemiology societies and organisations, national and international in scope. The JPC-SE originated in 2006 at the 2nd North American Congress of Epidemiology to coordinate and unify
Editorial on Asbestos Statement

A call to action: epidemiologists assert themselves with scientific data

Stanley H. Weiss

Editorial

A broad range of epidemiology organizations came together for the first time to clearly state that all forms of asbestos are harmful and causally related to disease and death. The Position Statement on Asbestos from the Joint Policy Committee of the Societies of Epidemiology (JPC-SE) was released on July 24, 2012. The Statement has rapidly garnered worldwide support. It calls, without any equivocation, for all mining, trade, and use of asbestos to cease. How did this come about? What does it portend for the future with respect to a role for epidemiologists in policy matters?

Epidemiologists understand and practice the science is requisite to anticipate and avoid long-term detrimental effects and to promote enduring changes.7 Systems thinking utilizes a framework for seeing interrelationships and patterns of change, rather than snapshots. This framework helps to identify areas where key data are required to formulate clear recommendations. Sometimes such information is not yet available to complete the picture. At other times, it is clear that the nuances of incremental data will not be likely to materially affect the conclusions. Systems thinking approaches also require the consideration of long-term horizons. Epidemiologists demand an array of knowledge gleaned from multi-
The JPC-SE Position Statement on Asbestos: A Long-Overdue Appeal by Epidemiologists to Ban Asbestos Worldwide and End Related Global Environmental Injustice

doi: 10.1289/ehp.1306892

Recently, the Joint Policy Committee (JPC) of the Societies of Epidemiology (SE), a consortium of national and international epidemiologic societies and organizations, released a statement calling for the global ban of asbestos use (JPC-SE 2012). This is not the first such call for an international ban (Collegium Ramazzini 2010), but it is a significant one because it is endorsed by 10 member organizations of the JPC-SE, numerous major epidemiologic and public health associations, and many epidemiologists (JPC-SE 2012). This position statement also highlights a case of global environmental injustice on a massive scale.

For decades asbestos has been known to cause lung cancer, mesothelioma, and other respiratory and cancerous conditions (LaDou et al. 2010). Asbestos exposure was the number one occupational health problem until its use was banned in most of the developing world (International Ban Asbestos Secretariat 2012). As a legacy of past asbestos use, the number of cases of asbestos-related diseases continues to climb every year across Canada and in many other industrialized countries with established markets in countries that have inadequate legislation and weak public health programs and environmental organizations, enabling the sale of asbestos products. One of the most extreme examples of such global injustice is Canada, which discouraged the use of asbestos-containing products in Canada but allowed the export of these same products until September 2012 (JPC-ES 2012). Canada had also been a major global producer of chrysotile asbestos. This presents a double standard: Legislators actively protect their citizens from asbestos-containing products but do not ban the exportation of these deadly products, as if citizens from the less-developed countries are second-class global citizens.

In this age of globalization and access to information, the world has become a global village. Information can no longer be withheld from the lower-income countries and their people, and education can
Implications of Asbestos Statement

- Corporate defense experts and attorneys representing the asbestos industry should no longer claim uncertainty about the harm caused by asbestos.

- The IJPC-SE Position Statement is used to defend against the use of asbestos in many countries yet to ban its use.

- Canadian mining and export ceased in 2012.

- Available in Arabic, Chinese, Portuguese, Russian, Spanish.
Implications of Asbestos Statement

• During the development of asbestos statement, limitations to Conflict of Interest (COI) policies and disclosures uncovered

• When objections from an epidemiologist came forward, IJPC put the approval process on hold to closely examine all objections

• Later learned this objector was the Principal of a private consulting firm receiving funding from asbestos industry

• Member society policy groups and the IJPC found objections meritless

• IJPC-SE revamped the Statement to make more robust and with links to the primary literature
IJPC-SE Endorsed ISEE Call to Action on Lead

ISEE Call for Action for Global Control of Lead Exposure to Eliminate Lead Poisoning

Lead poisoning is one of the most pervasive, well-established, and preventable environmental hazards worldwide. We in the International Society for Environmental Epidemiology (ISEE) add, therefore, our voices to the call for a concerted global effort to eliminate lead poisoning.

We specifically call for:

1. The governments of all nations to:
   a. Ban the manufacture, import, and export of lead-containing fuels, paints, plumbing fixtures, and plastics;
   b. Vigorously explore replacements for the lead content, wherever possible, in other consumer and commercial products;
   c. Implement, to the greatest extent feasible, effective procedures to reduce occupational exposure to lead and its compounds, especially in mining, manufacturing, and construction;
   d. Implement, to the greatest extent feasible, effective procedures to reduce exposure to lead from environmental sources in low-income communities and in schools that serve these communities.

Epidemiology 2015
Special APHA Symposium on the Census

International Threats to the Mission of Public Health as Governments Dismantle/Erode the Census

ORGANIZER: Robin Taylor-Wilson
1st Speaker, Moderator: Shirley Cramer
2nd Speaker: Daniel L. Cork
3rd Speaker: Munir Sheikh
4th Speaker: Phil Sparks
PANEL DISCUSSION MODERATOR: Colin L. Soskolne
WRAP-UP: Robin Taylor-Wilson

American Public Health Association (APHA)
142nd Annual Meeting and Expo, New Orleans, LA
Healthography: How Where You Live Affects Your Health And Well-Being
November 15-19, 2014
Conflict of Interest

• Many peer reviewed publications and societies require written COI disclosure by authors

• No COI disclosure required:
  • Reviewers
  • Appointed/elected staff, officers, trustees, editors
MEDICAL JOURNALS AND INDUSTRY TIES

Competing interests in epidemiology

Colin L Soskolne professor emeritus, on behalf of Wael K Al-Delaimy, Kathleen Burns, Manley R Finch, James A Gaudino Jr, Bruce Lanphear, Mark Oremus, Leah Phillips, Kathleen Ruff, Stanley H Weiss, and Steve Wing

University of Alberta, Edmonton, AB, Canada T6G 2X4

We congratulate The BMJ for being among the first medical journals to implement a policy on declaring financial competing interests. The journal is a pioneer in recognising that

Although work on ethics in epidemiology has been ongoing since the 1980s, the International Society for Environmental Epidemiology (ISEE) and the International Joint Policy
Editorial on Climate Change

Kathleen Ruff: Climate change—UN fails to address industry influence

July 23, 2017

Climate change is widely recognized as the most urgent issue facing planet Earth. The scientific community is clear: we must take strong action to stop practices that are causing global warming or risk passing a tipping point. [1]

Yet instead of democratic leadership to protect the wellbeing of the planet ahead of all other interests, the UN is giving a stronger role to the fossil fuel industry in setting global climate change policy.

Currently, the UN Framework Convention on Climate Change (UNFCCC) makes no distinction between civil society groups and industry groups and has no policy on conflict of interest (COI). Corporate lobby groups who receive millions of dollars from the fossil fuel industry participate in UNFCCC meetings.

Officials assert that the UNFCCC is evidence-based and that organisations it allows to participate in its meetings are committed to advancing the goals of the UNFCCC.

The evidence shows, however, that industry organisations participating in UNFCCC meetings, such as the US Chamber of Commerce, the Competitive Enterprise Institute, and BusinessEurope have spent hundreds of millions of dollars obstructing action on climate change. They lobbied to weaken European climate action [2], to kill the US Clean Power Plan [3], and are suing a US city which voted not to allow a pipeline and terminal for oil from the Alberta Tar Sands. [4]

Both in academia [5] and in schools [6], fossil fuel companies are funding materials, speakers, research, training and events that cast doubt on the scientific evidence on climate change and undermine the goals of the UNFCCC. Yet they are being invited to play a bigger role and have greater influence at UNFCCC deliberations.
Invitations to Speaking Engagements

• Dr. Colin Soskolne plenary keynote speaker at 2016 Training Workshop on Ethics in Research, Policy Advocacy and Public Health-Related Policy Development (Hanoi, Vietnam)

• Testimony to the impact and reputation of the IJPSE-SE
This document, completed in October 2011, consists of a letter in response to the US Department of Health and Human Services (HHS) “Advance notice of proposed rulemaking” (ANPRM) dated July 26, 2011 in regard to revising and updating HHS human subject research protections.

This letter provides opinions and recommendations from several epidemiology organizations and senior epidemiologists.

Our Document ID: HHS-OPHS-2011-0005-1066
Document Type: Public Submission
This is comment on Notice: Human Subject Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators
Docket ID: HHS-OPHS-2011-0005

www.regulations.gov/#!documentDetail;D=HHS-OPHS-2011-0005-1066

Document Subtype: Public Comment
Status: Posted
Received Date: October 26 2011, at 09:50 PM Eastern Daylight Time
Date Posted: October 27 2011, at 12:00 AM Eastern Daylight Time
Comment Start Date: July 26 2011, at 12:00 AM Eastern Daylight Time
Comment Due Date: October 26 2011, at 11:59 PM Eastern Daylight Time
Tracking Number: 80f5d6b1
First Name: Stanley H.
Last Name: Weiss
Organizational Name: Joint Policy Committee of the Societies of Epidemiology
Our online comment field (searchable):
Press Release—US Travel Ban

Embargoed until March 16th, 2017, 5:00 PM EST

Through executive order ("the Order") of its President, the United States of America (USA) has changed its policy on travel and immigration, preventing some individuals, including scientists, from visiting the United States. As of March 15, 2017, the most recent Order will suspend the USA’s refugee program for 120 days, halt the issuing of new visas for 90 days to people from six Muslim-majority countries, and reduce the number of refugees allowed to enter the USA from 110,000 to 50,000 this year.

Representing 21-member societies of epidemiologists worldwide, the International Joint Policy Committee of the Societies of Epidemiology (IJPSE) is obligated to point out the serious implications of this Order for effectively promoting health and quickly responding to disease outbreaks.

The Order prevents travel for scientists and public health officials from six predominantly Muslim countries. The order threatens to erode the collaborative foundation of science and has already adversely impacted the work of scientists in these countries.

Diseases know no boundaries. The Order prevents travel of epidemiologists and scientists who are focused on a growing global health crisis.
Policy Brief on Firearm Violence Prevention

INTERNATIONAL
JOINT POLICY COMMITTEE
OF THE SOCIETIES OF EPIDEMIOLOGY
Health for all through ethical, independent and transparent science

The Role of Epidemiology in Firearm Violence Prevention:
A POLICY BRIEF

Executive Summary:
Firearm violence is pandemic. Injury and death rates associated with privately-owned guns and firearms (hereinafter referred to as “firearm violence”) are high and continue to rise globally.1–3

Society cannot be satisfied with treating victims’ physical and psychological wounds; more must be done to prevent firearm violence and to address the societal circumstances that facilitate and enable it. Epidemiologists, as public health scientists, could do more to help prevent firearm-related injury and death by producing evidence to address its causes.

Owing to an absence of data and insufficient research funding, public
Policy Briefs Currently in Development: Opportunities to Provide Input

• Gender equity in academia/epidemiology

• Big data

• Climate change and health

• E-cigarettes
How do we disseminate information?

• Publications
• Invited presentations
• Symposia
• Through our member societies/associations
• Website
• Letters to governments and agencies
Summary

• Over first decade, the IJPC-SE has published articles in the peer-reviewed literature, developed policy briefs, and organized symposia/workshops in various countries

• Interest continues to grow, with society membership from around the world
How to Reach Us?

International Joint Policy Committee of the Societies of Epidemiology

Our Members

Interested in joining us? Click here for more info.

- American Academy of Pediatrics — Section on Epidemiology, Public Health and Evidence (AAP-SOEPE)
- American College of Epidemiology (ACE)
- American Public Health Association, Epidemiology Section (APHA-Epi Section)
- Australasian Epidemiological Association (AEA)
- Brazilian Association of Public Health (Associação Brasileira de Saúde Coletiva) (ABRASCO)
- Cameroon Society of Epidemiology (CASE)
- Canadian Society for Epidemiology and Biostatistics (CSEB)
- Collegium Ramazzini (CR)
- Council of State and Territorial Epidemiologists (CSTE)
- German Society for Epidemiology

What is Epidemiology

What is the IJPC-SE

What We Do

Our Core Values

Our Vision

Our Mission

Our Tag Line

What's New?

- [August 13, 2017] The updated list of endorsers to the IJPC-SE’s Call for Action on Lead is provided through the willing offices of Kathleen Ruff, Expert Adviser to the Chair and the Executive Committee, the IJPC-SE. Click here for more information.

- [July 26, 2017] Learn about the troubling accusations of a reporter teaming up with industry to cast doubt on the work of the WHO’s International Agency for Research on Cancer (IARC) here.

- [July 21, 2017] Climate change—UN fails to address industry influence by Kathleen Ruff was published by the BMJ on July 21, 2017.

An "opinion piece", the article describes the role being played at the meetings of the UN Framework Convention on Climate Change (UNFCCC) by lobby organisations representing the interests of fossil fuel and other industries.

It also addresses the refusal of the UN and countries from the global North to allow the adoption, or even any discussion, of a policy on conflict-of-interest. The integrity and mission of the UNFCCC are in grave peril.