



International Epidemiological Association

European Epidemiology Federation

<http://www.iea-europe.org>

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Letter from the Chair

At the next World Congress of Epidemiology (WCE 2014 in Anchorage), Prof. Joan Mackenbach of Erasmus University, Rotterdam will introduce the European regional session “Politics, Policies and Health Inequalities” which has been organized by the IEA-EEF and which will be held on Tuesday, August 19th. The theme is of great importance and high topicality not only for Europe, but also for the world.

It is a painful and troublesome truth that social inequities and health inequalities are

growing in most countries in the world. Fighting them is becoming the main challenge for governments for the next decades even in the more advantaged countries, in which, although social and economic conditions have generally improved, social inequities have widened. Epidemiologists have an important role in defining adequate approaches to better understand the determinants of these inequalities and producing cogent and irrefutable evidence for urgently needed action. European institutions must focus on this.

Concerns regarding the drafting of the EU’s health research programme for 2014-2015 of the health research programme “Horizon 2020” have been expressed by the IEA, ISEE-Europe, EPHA, and EUPHA in a joint letter to the EC commissioner. Assurances that public health and health systems research are of priority have been received. The hope is that the dialogue continues to benefit the already very advanced planning for Horizon 2016-2017.



The moon over Ponte Vecchio “What is the night? Almost at odds with morning, which is which” (Photo Copyright 2014: H Støvring)

The EU regulation for the protection of individuals’ data is another topic under the concerned gaze of epidemiologists and public health researchers, today. On March 12th 2014, the European Parliament cemented the strong support previously given at committee level to the European Commission's data protection reform by voting in plenary with

621 votes in favour of the regulation, 10 against and 22 abstentions. To become law the proposed regulation has to be adopted by the EU Council which includes negotiation with the newly elected parliament. Epidemiological and public health associations must lobby their national government's parliamentarians in order to make changes in the text to define separate rules for commercial and scientific purposes and favour epidemiological research conducted by public health institutions (see below the comment by the Swedish epidemiological society).



IEA-EEF board meeting in Florence: (left to right) David Batty, Robert West, Christoph Junker, Magnus Stenbeck, Henrik Støvring, Henrique Barros, Adele Seniori Costantini, Eva Grill, Fernando Benavides, Biljana Kocic.

The long standing tradition and the high level of epidemiological research in Europe is a valuable resource for society. However, in Eastern European countries, epidemiological resources are relatively less developed. Some efforts have been made to encourage the participation of Eastern European epidemiologists in epidemiological activities. The offer of financial support for those from Eastern European countries wishing to attend the EEPE course, held annually in Florence, however, has not been taken up by any epidemiologists. We must devote attention to identify more attractive and appropriate initiatives. The most obvious way to engage with Eastern European epidemiological communities is to hold conferences in the region (for example, the next Euro-conference

in 2018) A shorter version of the EEPE course (like a weekend-long event) held annually in different Eastern European cities might be a way forward.

The IEA (and IEA-EEF) constitute a valuable resource and they need to be reinforced. Increasing membership is an extremely relevant, even if difficult, goal in a period of financial crisis. Specifically for the EEF favouring communications through the renewed website and newsletter, and fulfilling its principal objective of holding regional conferences on the occasion in each of the non-WCE years and regional sessions seem suitable and attainable ways to contribute to the development of epidemiological activities. I wish to thank all friends of the EEF board with which I have shared thoughts and opinions on how to face commitments and accomplish our goals and who have helped me in this three year period in identifying proposals and realizing initiatives. Last but not least, I extend a big welcome to Elisabete Weiderpass, the elected IEA European councillor. I'm confident she will develop new ideas and projects. In the passing the baton, I give her my best wishes for fruitful and pleasant work.

Adele Seniori Costantini

Chair of the IEA European Epidemiology Federation (IEA EEF), European Councillor, International Epidemiological Association (IEA)

The proposal for new data protection legislation revisited – comment from Sweden

The proposal for a new data protection legislation for Europe has triggered a lot of debate throughout the research community. Currently European data protection is handled by a directive from 1995 (EC/95/46) according to which each member state in the union has to create its own legal system that protects

individual integrity with respect to how personal data are used and distributed to others. For several years this directive has been criticized for not keeping up with the rapid changes in the information society, such as efficient and fast computers, laptops, smartphones, etc., and with the associated growth of social media as well as professionally used tools to share data on a much more efficient and faster scale than hitherto possible. The heterogeneity of the data protection legislation across EU member states had led to difficulties in sharing data across borders. Among other things, this made it difficult for some epidemiological cross-border projects and led to an uncertain situation for data subjects who are treated differently and have different rights depending on which member state has their data. It should be emphasized, however, that the concerns have mainly had commercial and administrative applications as its object and that the leaping technical development has not resulted in any important weakening of the rights of research subjects.

Therefore, in 2012 the European Commission proposed a new common legislation across the EU (rather than a directive). The proposal aims at providing strengthened personal influence and homogeneous rules regarding personal data protection throughout the European community.



While this is a good cause in general, the needs of epidemiological and medical research as well as academic research in

general has been largely forgotten or ignored in the proposal - in particular for research that uses large population based material for which there is no possibility to consult each individual personally. This precarious situation was even worsened by the amendments put forth by the Civil Liberties and Home Affairs Committee which were accepted by the European parliament on March 12, 2014.

The greatest threat to health promoting research in the current proposals from the commission and the parliament is the absence of a general clause that will make research use of personal data legal, even if the data was originally collected for other purposes. Such a general research exemption is present in the current directive, but is lacking in both the commission and the parliament version of the legislation. Keeping the research exemption is essential for the continuation of epidemiological and other research aiming at protecting life and improving living conditions for the people of Europe by using the available big data sources for research.

Other changes of the proposed text is needed as well, such as relaxing the requirements of pseudonymization of data when this is necessary in order to perform qualitative unbiased health research, or to remove the especially restrictive rules regarding health data introduced by the parliament in their proposed Article 81.2. Our commentary in an upcoming issue of the European Journal of Epidemiology details the changes that are needed in order to preserve the possibilities to perform research based on personal data in the future.

The Wellcome Trust has recently put out a statement requesting that researchers demand a return to the original commission text in favor of the parliament proposal, and the European University Association supports this statement (REF).

We think that this requirement is insufficient, since the research exemption is lacking from both of these texts. We propose instead that epidemiologists seek to ask their government representatives to work towards the reintroduction of the research exemption in the Council of Ministers version of the text which is currently being negotiated among the national governments. This upcoming text will, when completed, be used as the council input to the joint discussions (the so-called “trilogue”) between the commission, the new parliament, and the council in the fall of 2014!

On behalf of the Swedish Epidemiological Society

Magnus Stenbeck, Olof Nyrén, Elisabeth Strandhagen, Eva Andersson, Juan Merlo, Jeong-Lim Kim, Anna Jöud, Jonas Björk, Anneli Ivarsson, Anna Oudin, Martin Englund

Endorsed on behalf the Spanish Epidemiological Society

Fernando Garcia Benavides

Endorsed on behalf the Finnish Epidemiological Society

Tomi-Pekka Tuomainen

Endorsed on behalf of the German Epidemiological Society

Henry Völzke

See also:

Nyrén O, Stenbeck M, Grönberg H. The European Parliament proposal for the new EU General Data Protection Regulation may severely restrict European epidemiological research. *Eur J Epidemiol.* 2014 May 7. [Epub ahead of print] PubMed PMID: 24802287.

Course Genomic and epigenomic epidemiology: still a few places left!

George Davey Smith and Caroline Renton (University of Bristol) will be teaching their excellent course on “Genomic and epigenomic

epidemiology: role in life-course research and causal inference” in Florence from 16 June – 20 June 2014. There are still a few places left!

<http://www.eepe.org/>

European Congress of Epidemiology 2015 in Maastricht: Healthy Living

This congress brings together scientists from a broad range of health care fields. Topics include methodological developments and state-of-the-art applications of epidemiology in a variety of clinical and public health research settings all contributing to Healthy Living.



3rd German Collaborative Summer School in Epidemiology, 28 July – 1 August 2014

The German Collaborative Summer School in Epidemiology is organised under the auspices of the German Society for Epidemiology (Deutsche Gesellschaft für Epidemiologie - DGEpi) and is based on a collaboration of currently five universities in Münster, Greifswald, Bremen, München, and Bielefeld, Germany. The school concept incorporates the long-term summer school, and bachelor and master level teaching experiences in epidemiology of these five partners and is oriented towards a preparation for the

challenges to epidemiology in a changing world. The 3rd German Collaborative Summer School in Epidemiology takes place between 28 July and 1 August 2014 in Bremen, Germany, and is organized by the Leibniz Institute for Prevention Research and Epidemiology – BIPS. This year’s summer school focuses on methods and modern applications of epidemiology and will communicate theoretical and practical experiences in epidemiological research - from study design to statistical analysis. Courses will cover cardiovascular, life course and applied pharmaco-epidemiology in addition to statistics in epidemiology, and will be held by international experts from the US, the UK and the Netherlands in addition to contributions from BIPS staff. The working language will be English and the course are oriented towards the needs of health professionals, scientists and students interested in epidemiology, prevention, and public health. We invite you to spend a sunny summer week in beautiful Bremen, learning and enjoying academic life! Please visit the website for further information:

www.bips-institut.de/weiteres/summer-school-2014.html

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Note from the Editors

At the beginning of this year IEA-EEF launched its new website design (www.iea-europe.org). Please have a look and discover our latest news, epidemiology mastercourses and institutes in Europe and much more. You can also follow us on twitter to keep updated on European epidemiology events and vacancies. If you have any news for the website or if you want us to post an event or vacancy on twitter, please e-mail it to: Eva.Grill@med.uni-muenchen.de



In depth comparative breakfast research: Italian and Bavarian. Which is which? For hints please refer to:

Eva Grill

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