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# DESorientering

Dansk Epidemiologisk Selskabs Nyhedsbrev

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Dansk Epidemiologisk Selskab

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**Ny foruroligende udvikling i EU's lovttekst om databeskyttelse**

DES HAR LØBENDE HOLDT MEDLEMMERNE ORIENTERET OM UDVIKLINGEN I DET NYE DIREKTIV/REGULATIV OM DATABESKYTTELSE. VOR OPFATTELSE VAR, AT DENNE TEKST VILLE TILLADE BRUG AF REGITERDATA I FORSKNING OG GENBRUG AF FORSKNINGSDATA OG BIOLOGISKE MATERIALER, SELVOM DER IKKE ER ET EKSPPLICIT INFORMERET SAMTYKKE TIL DENNE FORSKNING. JAN ALBRECHTS ÆNDRINGSFORSLAG KAN HELT ÆNDRE DENNE SITUATION – SE HANS ÆNDRINGSFORSLAG OG BEMÆRK ISÆR AMENDMENTS 15, 17, 19, 22 OG 31. SE OGSÅ WELLCOME TRUST'S VURDERING AF DENNE TEKST.

Jørn Olsen

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**Wellcome Trust's Vurdering af Jan Albrechts ændringsforslag**

Jan Philipp Albrecht, rapporteur for the LIBE committee, who is leading the progress of the Regulation through the European Parliament has produced his draft report on the Regulation ([http://www.europarl.europa.eu/meetdocs/2009\\_2014/documents/libe/pr/922/922387/922387en.pdf](http://www.europarl.europa.eu/meetdocs/2009_2014/documents/libe/pr/922/922387/922387en.pdf)). The rapporteur's report proposes 350 amendments to the draft. A number of these have serious implications for health research, based on the rapporteur's premise that "processing of sensitive data for historical, statistical and scientific research purposes is not as urgent or compelling as public health or social protection."

Were the amendments to pass, the major concern is that they would mean that identifiable health data about an individual could never be used without their consent. This would mean that much important epidemiological research could not take place and would also affect recruitment to clinical trials. The amendments would allow Member State to pass a law permitting the use of pseudonymised/key-coded data without consent, but only in cases of "exceptionally high public interest". (Amendment 27, p24; Amendments 327 and 328, p194-195; Amendments 334-337, p198-200.)

In addition, the amendments would bring all pseudonymised/key-coded data within the scope of the Regulation, even where the person or organisation handling the data does not have the key. This would significantly increase the regulatory burden on organisations using pseudonymised data or sharing these data with collaborators in countries outside the EU. (Amendments 13 and 14, p15-16; Amendments 84 and 85, p63-64).

MEPs will now consider and vote on the amendments over the next few months and I am working with the Federation of the European Academies of Medicine and other organisation to minimise the impact of these amendments.

We are collecting case studies of research that would be affected by these proposals. If you have any suggestions from Denmark that we could include, I would be very pleased to hear them. I would also be interested to know what the reaction has been in Denmark and other Scandinavian countries, where this would have enormous impact.

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With best wishes,

Beth

Dr Beth Thompson

Policy Adviser

Wellcome Trust

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## **Foredrag af Jun Jim Zhang**

### **Professor, Director Jun Jim Zhang**

*Shanghai Key Laboratory of Children's Environmental Health, Xinhua Hospital, Shanghai Jiao Tong University School of Medicine, Shanghai, China* will **February the 27<sup>th</sup>** give a lecture on **"Defining normal and abnormal fetal growth: promises and challenges"**, 3-4PM at Aarhus University. Professor, Director Jun Jim Zhang is currently the Chinese partner in the international FETOTOX project (<http://fetotox.au.dk>), supported by the Danish Strategic Research Council.

Professor, Director Jun Jim ZHANG Graduated from Shanghai Medical University in 1988; obtained PhD degree in epidemiology from the University of North Carolina at Chapel Hill, U.S. in 1993. He was an Assistant Professor at the Mount Sinai School of Medicine, New York; and an Investigator and, then, a Senior Investigator at the National Institute of Child Health and Human Development, National Institutes of Health (NIH), Bethesda, USA from 1997 to 2011. He was granted NIH tenure in 2005. He served as a member of Advisory Boards of the NIH Reproductive Medicine Research Network and Neonatal Research Network, the World Health Organization (WHO) Consultant on Reproductive Health; received NIH Merit Award twice. His research focuses on reproductive and perinatal epidemiology.



Currently, he is the Director of Ministry of Education – Shanghai Key Laboratory of Children's Environmental Health, Xinhua Hospital, the Shanghai Jiao Tong University School of Medicine; and WHO Consultant. He has conducted a number of observational studies and clinical trial

and published over 150 papers in prestigious journals including *New England Journal of Medicine*, *Lancet* and *JAMA*.

***Please send your registration before February the 10<sup>th</sup> to Liselotte Ovesen [LO@FOLKESUNDHED.AU.DK](mailto:LO@FOLKESUNDHED.AU.DK) and she will inform you about the location.***

Foredraget er åbent for medlemmer af DES, tilmeldingen er gratis men påkrævet.

Og husk Den Europæiske Kongres i august: [www.euroepi2013.org](http://www.euroepi2013.org)

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### **Om Dansk Epidemiologisk Selskab**

Dansk Epidemiologisk Selskab (DES) er et videnskabeligt selskab med det formål at arbejde for en tværfaglig præ- og postgraduat uddannelse og forskning inden for epidemiologi, at fremme det videnskabelige samarbejde mellem selskabets medlemmer, og at fremme videnskabeligt samarbejde med andre videnskabelige selskaber. DES er medlem af Dansk Medicinsk Selskab og er desuden den nationale afdeling af IEA.

DES optager medlemmer med alle relevante uddannelser. Indmeldelse kan ske via selskabets hjemmeside på [www.dansk-epidemiologisk-selskab.dk](http://www.dansk-epidemiologisk-selskab.dk). Årskontingentet er 225 kr., som opkræves via DADL. Henvendelser til DES kan rettes til bestyrelsens medlemmer eller vores email [des@soci.au.dk](mailto:des@soci.au.dk). Se i øvrigt vores hjemmeside for yderligere oplysninger.

For yderligere information om DES' historie henvises til en artikel skrevet af Marianne Schroll og Thorkild IA Sørensen i Ugeskrift for Læger i 1983; 145: 943-44. Af denne artikel fremgår det, at DES begyndte sit virke i 1974 i gruppen omkring befolkningsundersøgelserne i Glostrup. Denne gruppe blev sammen med andre til en officiel forening under organisationen af Lægevidenskabelige Selskaber (LVS) med direktøren for DIKE, Ole Horwitz, som den første formand i 1976 og med et sæt vedtægter, der fortsat er i brug.

### **DESorientering**

Selskabets nyhedsbrev DESorientering udkommer 2-4 gange årligt i et oplag på ca. 500 og udsendes til alle medlemmer via e-mail. Der er ingen copyright, men anvendelse af indholdet bedes altid ledsaget af en kildeangivelse. Materiale, som ønskes optaget i DESorientering, bedes sendt til [des@soci.au.dk](mailto:des@soci.au.dk).

Jørn Olsen på vegne af bestyrelsen i DES

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