

Dear Sir,

Some of Europe's most important medical discoveries, such as establishing the link between smoking and cancer, would not have been possible without using personal data. Countless lives have been saved and our growing understanding continues to improve health.

Disproportionate limits on the use of personal data in health research have been proposed to the EU Data Protection Regulation that would threaten crucial studies across Europe. It's critical these restrictions are not included in the final version of the law.

Protecting privacy is vital. Strong safeguards and governance structures already exist to help ensure that personal information is used safely, ethically and securely in research.

We urge the European institutions to ensure that the Regulation works with these safeguards to strike an appropriate balance that protects the interests of individuals while enabling research that benefits us all.

Yours

Dr Harpal Kumar, Chief Executive, Cancer Research UK

Dr Wendy Yared, Director, Association of European Cancer Leagues

President Anders Overgaard Bjarklev, Chairman of the Danish Rectors' Conference - Universities Denmark

Prof Peter Strohschneider, President of the German Research Foundation (DFG)

Professor Martin McKee CBE FMedSci, President, European Public Health Association (EUPHA)

Professor Françoise Meunier, European Organisation for Research and Treatment of Cancer (EORTC)

Professor Gilles Vassal, President of SIOPE , European Society for Paediatric Oncology

Dr Katrín Fjeldsted, President of the Standing Committee of European Doctors / Comité Permanent des Médecins Européens

Professor Jane Elliott, CEO, Economic and Social Research Council

Dr Jeremy Farrar, Director, Wellcome Trust

Professor Elisabete Weiderpass, Chair, European Epidemiological Federation

Nina Renshaw, Secretary General , European Public Health Alliance

Professor Jos van der Meer, President of the European Academies Science Advisory Council (EASAC)

Professor Bernard Charpentier, President of the Federation of European Academies of Medicine (FEAM)

Professor Phil Quirke FMedSci, President of the Pathological Society of Great Britain and Ireland

Dr Suzy Lishman, President of the Royal College of Pathologists

Stefan Bergh, Secretary General of the Swedish Cancer Society

Maggie Wilcox, President of Independent Cancer Patients' Voice

Dr Graham Love, Chief Executive, Health Research Board Ireland

Nicola Dandridge CBE, Chief Executive, Universities UK

Dr Janet Valentine, Director of Clinical Practice Research Datalink (CPRD)

Professor Sir John Savill, Chief Executive, Medical Research Council

Jørgen Vestbo President, European Respiratory Society

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Professor Ronan Lyons MD FFPH, Director of The Farr Institute of Health Informatics Research

Professor Andrew Morris FRSE FMedSci, Director The Farr Institute of Health Informatics Research

John Chambers, CEO of the Archives and Records Association (UK and Ireland)

Professor Peter Jones on behalf of NIHR CLAHRC Directors

Professor Dame Jessica Corner, Chair of the Council of Deans of Health

Professor Iain Cameron, Chair of the Medical Schools Council

Professor Naomi Fulop, Chair of Health Services Research UK

Professor Sir Robert Lechler, Executive Director King's Health Partners

Professor Steve West, Chair of Universities UK Health Education & Research Policy Network

Professor Rob Webster, Chief Executive, NHS Confederation

Professor Sir Michael Stratton, Director, Wellcome Trust Sanger Institute

Cynthia Joyce, CEO - MQ: Transforming mental health

Elisabetta Zanon, Director of the NHS European Office

Hans H. Storm, MD, Medical Director and Vice CEO, Danish Cancer Society

Ashley Gamble, Executive Director, Children's Cancer and Leukaemia Group

Steve Ford, Chief Executive, Parkinson's UK

Professor Jørgen Vestbo DMSc FRCP FERS, President of the European Respiratory Society (ERS)

Dr Hilary Burton, Director, PHG Foundation

Professor Jane Dacre, President, Royal College of Physicians of London

Professor Sierd Cloetingh, President of the Academia Europaea

Carl-Henrik Heldin, Director, Uppsala Branch of the Ludwig Institute for Cancer Research Ltd

Bartha Maria Knoppers, Director, Center of Genomics and Policy (CGP), McGill University

Anne Marie Tassé, Executive Director, Public Population Project in Genomics and Society (P3G)

Lau Caspar Thygesen, President, Danish Epidemiology Society

Peter Goodhand, Executive Director, Global Alliance for Genomics and Health

Nicola Bedlington, Secretary General, European Patients Forum

Sally Light, CEO, Motor Neurone Disease Association

Professor Paul Workman, Chief Executive, The Institute of Cancer Research, London

Maggie Blanks, Chief Executive of Pancreatic Cancer Research Fund

Dr William Duncan, Chief Executive, The Royal Society of Edinburgh

Richard Bergström, Director General, European Federation of Pharmaceutical Industries and Associations

Aisling Burnand Chief Executive, Association of Medical Research Charities

Professor David Ford, Director SAIL Databank, Professor of Health Informatics

Professor Peter Groenewegen, Director, NIVEL - Netherlands Institute for Health Services Research

Dr Laurent Castera, Secretary-General of EASL - European Association of the study of the liver

Nicola Dandridge CBE, Chief Executive, Universities UK.

Professor Sir John Tooke PMedSci, President, Academy of Medical Sciences

Professor Rolf Tarrach, President, European University Association

Lesley Wilson, Secretary General, European University Association

Professor Günter Stock, President of All European Academies (ALLEA)

Dr Sakari Karjalainen, Secretary General of the Cancer Society of Finland

Beverly Searle PhD, Chief Executive Officer – Unique

Michele Acton, Fight for Sight Chief Executive

Alison Clough, Acting CEO, Association of the British Pharmaceutical Industry

Professor Peter Diggle, President, Royal Statistical Society

Alastair Kent OBE, Director, Genetic Alliance UK and President, EGAN

Anders Hamsten, Professor and Vice-Chancellor of the Karolinska Institutet

Professor Per Hall, Karolinska Institutet and Chairman Populations Research Committee, Cancer Research UK

Hans-Gustaf Ljunggren, Professor, Dean of Research, Karolinska Institutet

Nancy Pedersen, Professor, Karolinska Institutet; Chair International Advisory Board, Farr Institute UK

Professor Jamie Hacker Hughes President, British Psychological Society

Baroness Delyth Morgan, Chief Executive, Breast Cancer Now

Camilla Stoltenberg, Director-General of the Norwegian Institute of Public Health, Oslo, Norway

Juleen Zierath, Professor at Karolinska Institutet, Stockholm, Sweden

Professor Gerrit A. Meijer, Scientific Director BBMRI-NL, Chairman of the Scientific Advisory Board Dutch Cancer Society

Dr Isabel Noguer Zambrano, Director, National Centre for Epidemiology Spain

Anne-Marie Engel, Director of Research, Lundbeck Foundation

Simon Gillespie Chief Executive, British Heart Foundation

Roger Paul, Chairman of Trustees, Bone Cancer Research Trust

Sandra Currie, Chief Executive, Kidney Research UK

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Dr Cor Oosterwijk, Director, VSOP (Dutch Genetic Alliance)

Professor Derek Alderson, Vice President, Royal College of Surgeons

Professor Augustin Ferrant, Perpetual Secretary, Royal Belgian Academy of Medicine (ARMB)

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Ildfonso Hernández, Past president of SESPAS, Spanish Society of Public Health and Health Administration

José Ramón Martínez, President of AEC, the Community Nursing Association (Spain)

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Josefa Cantero, President of Juristas, the Health Jurists Association (Spain)

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María García, President of HIPATIA, Andalusian Association of Public Health and Sanitary Administration (Spain)

Rosa Magallon, President of REAP, Spanish Primary Care Network

Roman Garcia, President of SCSP, Canary Society of Public Health (Spain)

Esteve Fernandez, President of SEE, Spanish Society of Epidemiology

Raimundo Mateos, President of the Spanish Society of Psychiatric Epidemiology

José M^a Ordóñez, President of SESA, Spanish Society of Environmental Health

Cati Chamorro, President of SCBSP, Public Health Society of Catalonia and the Balearic Islands (Spain)

Sarah Lindsell, CEO, The Brain Tumour Charity

Professor Pascual Parrilla, Director of the Institute of Biomedical Research of the Murcia Region, Spain.

Dr Liam O'Toole, Chief Executive Officer, Arthritis Research UK

Hilary Evans, Chief Executive, Alzheimer's Research UK

Pascal Soriot, Chief Executive, AstraZeneca

Mr Ed Owen, CEO, Cystic Fibrosis Trust

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Tracey Brown, Director, Sense About Science

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Sir John Skehel FMedSci FRS, Vice-President of the Royal Society

Dr Stephen Brett, President, the Intensive Care Society

Professor Julia Brown, Director, The UKCRC Registered CTUs Network, on behalf of UKCRC Registered CTUs

Professor Dame Valerie Beral DBE AC FRS, University of Oxford

Bjørn Henrichsen, Chair of the Board of Directors of the Consortium of European Social Science Data Archives

Professor Yves Levy, CEO and Chairman of INSERM, the French Institute of Health and Medical Research