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
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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
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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
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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
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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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Manuel Posada de la Paz MD, PhD Director, Institute of rare diseases research, Instituto de Salud Carlos II, Madrid, Spain
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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Ildefonso Hernández, Past president of SESPAS, Spanish Society of Public Health and Health Administration
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Pilar García-Gómez, President of AES, Health Economics Association (Spain)
Josefa Cantero, President of Juristas, the Health Jurists Association (Spain)
Miguel Carrasco, President of AMASAP, Public Health Association of Madrid (Spain)
María García, President of HIPATIA, Andalucian 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 Mª 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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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