

PRESS RELEASE

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NEW EU PROPOSALS THREATEN UK POVERTY RESEARCH

New data protection rules proposed in Europe could severely hamper research into UK poverty and deprivation, a group of charities will warn today [Tue 10 Feb] at a conference on poverty statistics.

Amendments to proposed data protection laws, currently being scrutinised by the European Parliament, would force researchers to seek explicit consent from anybody whose data is used in new health-related studies. That could mean asking thousands of families to agree to allow previously collected information to be used again in public health and poverty research, even if their identities are already masked.

But the implications of the proposals go far beyond healthcare research, applying stricter rules to the re-use of other types of data research too.

The charities – the Royal Statistical Society, Joseph Rowntree Foundation and Resolution Foundation – are concerned that further restricting access to health and social data will make it difficult to analyse the underlying causes of poverty and deprivation, making it harder to intervene effectively. A whole range of data could be made too bureaucratic to use, leaving a black hole in poverty research.

The issue will be highlighted at the ‘Poverty and deprivation: Statistics for Action’ conference in London, jointly-organised by the three organisations voicing concerns.

Research funding at risk

If the amendments are passed, it could put an end to many large-scale studies into social conditions and poverty, with millions of pounds of funding put at risk as research projects become too bureaucratic to continue.

The issue stems from the European Commission’s draft Data Protection Regulation, first published in 2012 but still being discussed by EU legislators. When it passes through the European Parliament and Council of Ministers, which may be later this year, it will take direct effect in all EU Member States. In the UK, the new law will replace the Data Protection Act.



In March 2014, the European Parliament adopted amendments to Articles 81 and 83, put forward by German Green MEP Jan Albrecht as Rapporteur for the Regulation, which would severely restrict the use of personal data for research purposes – particularly if it relates to health.

Albrecht wants the processing of medical data to be “permitted only with the consent of the data subject”, even if they have previously given permission for their details to be used for similar research. Even identity masked health records would need to meet tough conditions before they can be used, including meeting a new “high public interest” test and “if that research cannot possibly be carried out otherwise”.

A coalition of health charities has previously warned such new provisions will make using routine data and registries unworkable or completely impossible.

Commenting, Executive Director of the Royal Statistical Society Hetan Shah, said:

“Data privacy is extremely important, and people must have confidence their personal details are not being used improperly. But if this new rule is passed in Europe, it could effectively tie the hands of charities researching health-related poverty and deprivation in the UK, making the solutions even harder to find. I urge all British MEPs to listen to our concerns and push back against these plans.”

Matthew Whittaker, Chief Economist at the Resolution Foundation said:

“The first step towards tackling poverty is understanding it, and high quality data is essential for this. We are already impeded by a lack of timely and accurate data on many poverty related issues, and this new law could potentially make things worse.”

Aleks Collingwood, Policy and research Manager at JRF said,

“A robust evidence base is a necessary tool for seeking out the root causes of poverty. If we lose access to vital datasets it will be much more difficult to make targeted policy recommendations for the reduction of poverty.”

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The ‘Poverty and deprivation: Statistics for Action’ conference, organised by the Statistics User Forum (SUF) with Royal Statistical Society, Joseph Rowntree Foundation and the Resolution Foundation as partners, takes place on Tuesday 10 February at the RSS in London. For more details see: <http://www.statslife.org.uk/events/eventdetail/349/15/>

For more information on the legislation and its potential effects on health research, see: <http://www.wellcome.ac.uk/About-us/Policy/Spotlight-issues/Personal-information/Data-protection-legislation/index.htm>

The text of the Data Protection Regulation and the proposed amendments can be found at:



<http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2F%2FEP%2F%2FTEXT%2FBREPORT%2BA7-2013-0402%2B0%2BDOC%2BXML%2BV0%2F%2FEN&language=EN>

CONTACTS

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The Royal Statistical Society (RSS) founded in 1834 is one of the world's most distinguished and renowned statistical societies. It is a learned society for statistics, a professional body for statisticians and a charity which promotes statistics, data and evidence for the public good. Today the Society has 6000 members around the world. www.rss.org.uk

The Resolution Foundation is a non-partisan think-tank that works to improve the living standards of those in Britain on low to middle incomes. We conduct authoritative analytical research on living standards in the UK and produce effective policy solutions that help shape the debate on economic and social policy. www.resolutionfoundation.org

The Joseph Rowntree Foundation is a funder of research for social change in the UK. We aim to reduce poverty and strengthen communities for all generations. For more information visit www.jrf.org.uk

