

Realising the societal benefits of health research through the Data Protection Regulation (2012/0011(COD))

We welcome the provisions for research in the Commission's proposal for a Data Protection Regulation, which provides a proportionate mechanism for protecting privacy, while enabling important health research to continue.

The amendments proposed in the LIBE rapporteur's draft report would have devastating consequences for health research if accepted. Vital research from across Europe that produces benefits for public health and healthcare would not be possible if these amendments were to pass.

Health research is currently conducted under ethical safeguards, ensuring that individuals' privacy is appropriately reconciled with the benefits of research to society.

We recommend that:

- MEPs oppose the LIBE rapporteur's amendments that would prevent potentially life-saving research
- MEPs support amendments to further clarify and strengthen the provisions in the Commission's proposal (see amendments attached)

Case studies of research that would be prohibited or severely impaired by the LIBE rapporteur's proposed amendments are included in Annexes 1 and 2.

Introduction

We welcome the greater clarity for research in the Commission's proposal for a Data Protection Regulation, which provides a proportionate mechanism for protecting privacy, while enabling health research to continue. The Commission's proposal enables personal data to be processed for historical, statistical and scientific research without the need for consent or another legal basis, provided that it fulfils the requirements of Article 83.1.¹

The rapporteur of the LIBE committee (LIBE rapporteur) has proposed amendments that would have devastating consequences for health research if accepted. It is vital that MEPs maintain the Commission's original provisions to ensure that the Regulation strikes an appropriate balance between facilitating the safe and secure use of patient data in health research and the rights and interests of individuals.

Patient data is vital for research to improve public health and healthcare

Individual patient records provide a vital resource for health research for the benefit of society, such as understanding the factors underpinning health and disease. Such observational studies have led to breakthroughs such as understanding the association between smoking and lung cancer and informing treatment of infection in unborn babies (see annex 1, case studies 1 and 7).

¹ The conditions set out in Article 83 are that personal data should not be used if anonymous data would be sufficient and, if possible, any identifying information should be kept separately from other information.

Access to patient records also helps researchers identify suitable participants to invite to take part in studies. This is essential for evaluating new medicines, technologies and interventions for the prevention, diagnosis and treatment of disease, such as for screening for ovarian cancer (see annex 2, case study 8).

Health research with personal data takes place within a robust ethical framework supported by guidelines such as the international *Declaration of Helsinki*.² This ensures that an individual's personal data are only used in research when this is proportionate to the potential benefits for society as a whole. Project approval by an ethics committee is a particularly important safeguard when data are to be processed for research without consent of the data subject. This safeguard is not reflected in the current Commission proposal for a Regulation, which could be strengthened to clarify this.

The LIBE rapporteur's amendments will prevent valuable health research

The LIBE rapporteur's draft report³ proposes amendments that would have devastating consequences for health research:

- **Data concerning health could only be processed for research with the consent of the data subject** (amendments 27, 327 and 334-336)
- **Member States could pass a law permitting the use of pseudonymised data concerning health without consent, but only in cases of “exceptionally high public interest” and with authorisation of the competent supervisory authority** (amendments 328 and 337)
- **Pseudonymised data would be considered within the scope of the Regulation, even where the person or organisation handling the data does not have the key enabling re-identification**

The LIBE rapporteur's amendments would prohibit or severely impair research in the following ways:

Data concerning health could only be processed for research with the consent of the data subject (amendments 27, 327 and 334-336)

The LIBE rapporteur's amendments would mean that research would almost always require consent as the legal basis for the processing of personal data. Consent is an important ethical principle in health research. However, the Commission's proposal for a Regulation requires consent for processing to be “specific, informed and explicit”, which is often difficult to achieve in health research. The combination of the LIBE rapporteur's amendments and the requirements for consent is therefore highly problematic for research.

The need for “specific” consent is a particular problem. Many research resources such as biobanks, rely on broad consent where the participants give consent for their pseudonymised data⁴ to be used for a variety of research studies under certain conditions. This broad consent approach is approved by an ethics committee and reduces the burden on participants because they do not need to be contacted for consent for each new study. It also means that pseudonymised data in these

² WMA Declaration of Helsinki (2008) [Ethical Principles for Medical Research Involving Human Subjects](#)

³ [Draft report of the LIBE committee by Jan Philipp Albrecht](#)

⁴ Pseudonymised (or key-coded) data cannot directly identify an individual, but are provided with an identifier that enables the patient's identity to be re-connected to the data by reference to separate databases containing the identifiers and identifiable data. In health research robust safeguards are used to reduce the risk of re-identification from pseudonymised data.

resources can be reused many times by many different researchers to maximise the benefit of the investment by government funders and charities. These research resources would become very difficult, or impossible, to run if consent for processing had to be sought for every new research project. This would severely undermine much observational research.

In addition, in some studies it is not possible to seek consent, either because a very large sample size is needed to generate a robust result and this would be practically difficult to obtain, or because seeking consent would introduce bias. For example, a study of around 30,000 children, which was possible because consent was not required, demonstrated a possible link between living near power lines and the risk of leukaemia (see also annex 1 and annex 2, case studies 3, 5 and 6). Biases introduced through consent increase the chance of researchers reaching the wrong answer, with potentially dangerous consequences such as under- or overestimating the benefits of treatment. In addition, seeking consent in these cases usually means that the research would exclude the most isolated, the hardest to reach and the most deprived members of society; groups that often are likely to benefit most from the research.

In situations where consent for processing is not sought, it is particularly important that appropriate safeguards are in place, for example ethics committee approval. However, the LIBE rapporteur's amendments would stop this important research taking place altogether.

Member States could pass a law permitting the use of pseudonymised data concerning health without consent, but only in cases of “exceptionally high public interest” and with authorisation of the competent supervisory authority (amendments 328 and 337)

The narrow scope of the LIBE rapporteur’s research exemption will make some research impossible

The amendments proposed by the LIBE rapporteur will tightly restrict the scope for an exemption from consent. Member States could provide an exemption from consent only in the “exceptionally high public interest”. Health research clearly serves the public interest. However, the words “exceptionally high” suggest that the LIBE rapporteur intends the exemption to be used only in a very limited set of circumstances. This is likely to be problematic for many studies, particularly because the results and impact of the study are not known at the outset.

The amendments would introduce a requirement for a competent supervisory authority to authorise processing. Research with personal data should receive ethics committee approval before it starts, but this authorisation from a competent supervisory authority will add further bureaucracy and potential for delays.

The exemption would only apply to pseudonymised data. This means that research with identifiable data could *never* be used without consent, regardless of the safeguards in place. Pseudonymised data provide the basis for many research studies. However, in some cases pseudonymised data will not be sufficient for the research purposes. Sometimes researchers need details such as age, postcode and information on a health condition. Together, this information could disclose the identity of an individual but the study would not be possible without it, for example a study that showed an increased risk of leukaemia in children born near power lines (annex 1, case studies 6). It is very important that such research is conducted under appropriate safeguards, for example ethics committee approval, to ensure that the use of identifiable personal data without consent is proportionate to the potential public benefit. However, if the LIBE rapporteur's amendments are passed this research would never be able to proceed.

Researchers would be prevented from identifying individuals to take part in research

Pseudonymised data are often not sufficient to permit researchers to identify an individual to invite them to take part in an ethically approved study. In these instances researchers need access to the minimal amount of data required to identify eligible people and invite them to participate, subject to ethical, security and confidentiality requirements as for other research (annex 2, case study 8). The

actual research would only proceed subject to informed consent and with ethics approval. Research shows that the public are keen to hear about opportunities to participate in medical research,⁵ often for altruistic reasons, but people can only agree to join studies if they have been invited to participate. The LIBE rapporteur's amendments would outlaw this first step of inviting participation, which would seriously hamper the conduct of research.

Pseudonymised data would be considered within the scope of the Regulation, even where the person or organisation handling the data does not have the key enabling re-identification

The LIBE rapporteur's amendments clarify that pseudonymised data are included in the scope of the Regulation (amendments 14, 84 and 85). However, pseudonymised data would be subject to most of the same requirements as identifiable data, for example relating to international transfers. This would increase the regulatory burden for research and create a regulatory system that is not proportionate to the privacy risks to an individual.

Health research provides examples of good practice in the robust pseudonymisation of personal data to protect individuals' privacy. Pseudonymisation is important in research since it protects the privacy of data subjects while giving researchers access to important individual-level detail. For example, pseudonymised data allows connections to be made between different sources of information, for example to link work-related exposures and disease risk.

Safeguards are used to minimise the risk of re-identification from pseudonymised data in research, for example:

- encryption and key management to restrict access to the data;
- technical and organisational security measures; and
- the restriction of access to *bona fide*, trained researchers with contractual requirements and sanctions if they breach the conditions.

It is vital that the use of pseudonymised data in research is regulated proportionately, taking into account the minimal risk of re-identification when safeguards are in place. Proportionate regulation will facilitate the continued use of pseudonymised data in health research and incentivise data controllers to use pseudonymised data in preference to identifiable data, providing greater privacy protection.

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⁵ [Public Support for Research in the UK National Health Service \(2011\)](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3117733/)

ANNEX 1: The use of personal data concerning health without specific, explicit consent is sometimes essential for research for the health of populations

If researchers cannot process medical records for research without specific, explicit patient consent, they:

- **could not run cancer registries that record all cases of cancer** to help assess the levels of cancer risk in the whole population and in particular areas;
- **could not link records of new cancers to subsequent mortality rates** to help assess survival trends and any international differences in cancer survival rates;
- **could not monitor the cancer hazards caused by particular occupations**, such as demonstrating a high risk of fatal mesothelioma in those who worked in building or carpentry before 1980, probably due to using power tools on asbestos products;
- **could not monitor the hazards of medical procedures**, such as ordering a routine CT scan which has recently been shown through record linkage to increase the risk of developing cancer many years later;
- **could not monitor trends over time and differences between surgical mortality rates in different hospitals**, for example assessing trends in the risk of developing a blockage in a blood vessel in the lungs (embolism) in the months after routine surgery;
- **could not assess unexpected side-effects of routinely prescribed medicines**, for example appropriate record linkage has shown that oral contraceptives increase cervix cancer but to decrease endometrial and ovarian cancer to such an extent that oral contraceptives decrease the overall risk of getting cancer and of dying of cancer;
- **could not have reliably disproven the widespread belief abortions increase the risk of getting breast cancer later in life**;
- **could not identify people with a particular disease to study the avoidable causes of that disease**, for example identification of lung cancer patients through their medical records has been used in hundreds of studies around the world; and
- **could not identify sufficiently large numbers of people with a particular disease to invite them into trials of the treatment of that disease**, for example recruitment of 20,000 suitable people into the Heart Protection Study on statins that has helped transform medical practice throughout the world, which began with identification of 400,000 patients with a hospital record of arterial disease.

ANNEX 2: Case studies

1) The effect of toxoplasmosis treatment in pregnancy (Europe)

A study funded by the European Commission and involving multiple centres throughout Europe found evidence that prenatal treatment of toxoplasmosis had no effect on mother to child transmission of infection. This led to important policy changes in European countries. As this study used pseudonymised patient data, it may have never been conducted were the LIBE rapporteur's amendments to pass.

Toxoplasmosis is caused by infection with a parasitic worm that is found worldwide. In Europe, approximately 1% of non-immune pregnant women become infected, which may cause congenital (mother-to-child transmitted) disease. The evidence for the benefits of prenatal treatment is controversial and side-effects may harm the unborn child.

The European Multicentre Study on Congenital Toxoplasmosis (EMSCOT) was conducted to analyse the risks of transmission of toxoplasmosis, signs of damage in the child and how these risks are modified by prenatal treatment. Funded by the European Commission, this research used data from centres in Austria, Denmark, France, Italy and Poland. The research showed that prenatal treatment did not reduce mother to child transmission of infection and highlighted a lack of understanding about the balance between the risks and benefits of treatment. The research led to a large number of articles published in high profile medical journals and influenced policy on toxoplasmosis in a number of different countries:

- The Danish government decided to stop neonatal screening.
- Studies were initiated in France, particularly regarding the use of less toxic treatment regimens.
- Germany never implemented universal pre- or neonatal screening.
- Sweden and Switzerland decided not to implement neonatal screening.
- The UK National Screening Committee policy decided not to recommend screening for congenital toxoplasmosis.

EMSCOT used routinely collected clinical patient data from a large sample without requiring consent. Patient data was pseudonymised and allowed matching of follow up data to the same patient. If the LIBE rapporteur's amendments were implemented, the exemption for the use of pseudonymised data without consent would be so narrow that studies like this would probably not be able to go ahead.

More information can be found at:

<http://www.ucl.ac.uk/ich/research-ich/mrc-cech/research/studies/toxoplasmosis>

2) Improving treatment options for schizophrenia (Finland)

A Finnish academic research group found that inclusion of a drug that is regularly given to people with schizophrenia as part of a wider treatment regimen, increases mortality by 91% in these patients. Such registry-based research would be difficult if the LIBE rapporteur's amendments were to pass. This is because it would be difficult or impossible to obtain specific consent for the use of pseudonymised patient data that is needed for this kind of research.

Many people with schizophrenia are treated with multiple drugs to help them manage their condition. A study led by Finnish researchers analysed whether the use of different drugs has an impact on mortality in this patient group.

The study used data already available in Finnish registries, to show that different combinations of antipsychotic drugs do not increase mortality compared to treatment with just a single drug. As expected, antidepressants decreased mortality attributed to suicidal deaths. However, it was noted that additional treatment with the psychoactive drug benzodiazepine was associated with a 91% increased death rate amongst patients, which was due to both suicidal deaths as well as non-suicidal deaths.

Research studies are vital to determine the correct, safe and most effective therapy for patients. However, registry-based research often relies on pseudonymised data that was collected routinely from patients. Implementation of the LIBE rapporteur's amendments would mean that specific patient consent would have been needed for this study, unless it qualified for a narrow exemption. In this particular research study, seeking consent would likely have introduced such bias that results could not be relied upon and the study may not have gone ahead.

Further information on this study:

Tiihonen et al. (2012) *Polypharmacy with Antipsychotics, Antidepressants, or Benzodiazepines and Mortality in Schizophrenia*. Arch Gen Psychiatry. 69(5):476-483

<http://archpsyc.jamanetwork.com/article.aspx?articleid=1151489>

3) High blood pressure and preterm birth (Sweden)

A Swedish study found men who were born early during pregnancy to be a risk group for developing high blood pressure as adults. This study linked data from four different national registries, which would become difficult, if not impossible, upon implementation of LIBE rapporteur's amendments.

High blood pressure affects about 25% of adults worldwide and significantly increases the probability of suffering from a heart condition, stroke or other conditions. Several causes of high blood pressure have already been identified and many research studies are still trying to understand the underlying mechanisms.

A study led by Swedish researchers found a link between preterm birth and high blood pressure. The study retrospectively analysed pseudonymised data that was linked from four different Swedish databases for more than 300,000 men. It was concluded that babies born early during a pregnancy had a significantly increased risk of high blood pressure in adulthood. Fostering further research to investigate the connection of preterm birth and blood pressure may aid understanding of the underlying mechanism of this condition and lead to better control of high blood pressure in this risk group. In the EU, about 10% of all deliveries are preterm. As a consequence, this research field has the potential to save thousands of lives and reduce pressure on stretched health systems.

Epidemiological research based on routine patient data and patient registries is fundamental to identify risk factors for certain diseases amongst the population. These kinds of studies would be difficult, if not impossible, to conduct if LIBE rapporteur's amendments. Since the exemption from consent proposed by the LIBE rapporteur is so narrow, consent would be needed to use data that was routinely collected many years ago. However, it would be almost impossible to obtain consent from 300,000 people without introducing sample bias and incurring huge cost.

Further information on this study:

Johansson et al. (2005) *Risk of High Blood Pressure Among Young Men Increases With the Degree of Immaturity at Birth*. Circulation. 112: 3430-3436

<http://circ.ahajournals.org/content/112/22/3430.long>

4) Diabetes treatment and occurrence of cancer (Europe)

After urgent request from the European Medicines Agency, an ongoing study funded by the European Commission is investigating links between diabetes treatment and the occurrence of cancer. Due to the need for consent that the LIBE rapporteur's amendments would likely impose on this research, the study may be significantly inhibited.

The Caring (CAncer Risk and INsulin analogues) project is investigating links between drugs for diabetes and the emergence of cancer in those patients. It involves centres in Denmark, Finland, Netherlands, Norway and Sweden. The study is currently ongoing, initiated after urgent request from the European Medicines Agency and funded with more than €2.9 million under the Seventh Framework Programme from the European Union. Utilising high quality prescription databases and other national datasources, the aim is to determine the risk of insulin and insulin analogues on cancer development. It is therefore likely to serve as a solid base for new treatment recommendations and improved patient care.

Implementation of the LIBE rapporteur's amendments would be likely to significantly inhibit the Caring project because consent would likely be required from all data subjects to link their data across different sources. Consent would introduce bias into the results and it would be likely that the study could not continue unless it could rely upon an exemption.

Further information on this study can be found at:

http://cordis.europa.eu/search/index.cfm?fuseaction=proj.document&PJ_RCN=12267238

5) Lessons learned from German cancer registries (Germany)

German cancer registries suffered from new legislation introduced in the 1980s resulting in the temporary breakdown of the oldest cancer registry world-wide based in Hamburg, Germany. A similar phenomenon might be seen on a European scale if the LIBE rapporteur's amendments were adopted.

In the 1980s, informed consent was made a statutory requirement for inclusion of data in cancer registries in two German regions. Subsequently, it was reported that cancer registries in these regions were unable to collect more than 70% of cancer cases. The Hamburg registry, which had collected cancer data for over 50 years, broke down and was no longer able to add its results to international cancer indexes. These difficulties led to new guidance from the Federal Government in 1994, which relaxed the requirement for consent in all regions.

A similar detrimental effect on patient and disease registries could occur if the LIBE rapporteur's amendments were adopted. The need for informed consent from patients to add their data to a registry would mean that many existing registries could be expected to suffer similar challenges as the German registries in the 1980s. This would have significant effects on disease monitoring and the conduct of research across Europe. Further, since specific consent would be needed every time data from a registry was used in pseudonymised form, the value of registries would be severely undermined.

Further information can be found at:

Ingelfinger et al. (2004) *Registry research and medical privacy*. New England Journal of Medicine 350, 1542–3

<http://www.nejm.org/doi/full/10.1056/NEJMMe048027>

UK Academy of Medical Sciences (2006) *Personal data for public good: using health information in medical research*:

<http://www.acmedsci.ac.uk/download.php?file=/images/publication/Personal.pdf>

6) Power lines and occurrence of childhood leukaemia (United Kingdom)

A UK study found a link between high incidence of childhood leukaemia and proximity of birth place to high voltage power lines. This finding requires confirmation from follow-up studies, which would be difficult or even prohibited if the LIBE rapporteur's amendments were to pass.

Cancer is a major burden to global health and the chance of developing cancer increases with age. However, children also develop cancer and the underlying mechanisms are very diverse and only partially understood.

A UK study investigated whether proximity of home address at birth to high voltage power lines is associated with increased risks of childhood cancer. Cancer registries were used to identify children with cancer and linked with information on where the children lived. No active participation from data subjects was required. The data researchers needed for the study (disease status, age and post code), could enable the identity of individual children to be disclosed, therefore approval was obtained to use the data of 29,081 children with cancer without consent. The study showed that, compared with children who lived more than 600m from a high voltage power line at birth, those who lived within 200m had a 69% increased risk of developing leukaemia. The authors of this study stressed that there is no accepted biological mechanism to explain their findings and emphasised that the results may be due to chance or some other confounding factor.

The debate over whether there is a causal link between overhead power lines and childhood leukaemia will continue. What is clear is that, given the small numbers involved (annual incidence of childhood leukaemia in England and Wales is 42 cases per million), further studies will require access to data on a similar, or even larger, scale. This study and similar follow up studies would be difficult, if not impossible, if the LIBE rapporteur's amendments are implemented. This is because the studies rely on the use of identifiable patient data without consent. Furthermore, registries themselves are also likely to be undermined by the proposed amendments (see case study 5).

Further information on this study:

Draper et al. (2005) *Childhood cancer in relation to distance from high-voltage power lines in England and Wales:a case-control study.* British Medical Journal **333**, 1290–4.

<http://www.bmjjournals.org/cgi/content/full/330/7503/1290>

UK Academy of Medical Sciences (2006) *Personal data for public good: using health information in medical research:*

<http://www.acmedsci.ac.uk/download.php?file=/images/publication/Personal.pdf>

7) Understanding the link between smoking and lung cancer (United Kingdom)

Fundamental medical knowledge that has saved millions of lives was gained by research that would be difficult or impossible to conduct if the LIBE rapporteur's amendments were put into place. One example is the association of smoking and lung cancer that was discovered using data from patient records.

In 1947, Professor Sir Richard Doll CH OBE FRS FMedSci began a series of investigations into the link between smoking and lung cancer that would continue for over 50 years. Mortality data collected by the Registrar-General showed a phenomenal increase in deaths attributable to lung cancer in the first half of the 20th century. At the time, two main causes for this increase had been put forward: firstly, general atmospheric pollution from car exhaust fumes, from the surface dust of tarred roads and from industrial activities; and secondly, the smoking of tobacco. Sir Richard and his team were the first to undertake a study on a sufficiently large scale to determine whether lung cancer patients differed materially in terms of their smoking habits, or some other way that might be related to the pollution theory. Their study involved 20 London hospitals in which lung cancer patients were identified by clinicians who then forwarded the records to the research team. The team conducted extensive interviews with the identified patients around their lifestyle and smoking habits. Interviews were also conducted with sex and age matched non-cancer 'control' patients, who were also identified from medical records. In demonstrating the real association between lung cancer and smoking, the findings paved the way for further large-scale prospective studies carried out by Doll and others, including the Survey of British Doctors.

If the LIBE rapporteur's amendments were implemented, similar research would be very difficult to conduct. The consent of data subjects would be needed for researchers to identify suitable individuals to ask whether they wanted to participate in interviews.

Evidence of a link between lung cancer and smoking was published over 60 years ago:

Doll et al. (1950) *Smoking and carcinoma of the lung*. British Medical Journal 2, 739–48.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2038856/pdf/brmedj03566-0003.pdf>

UK Academy of Medical Sciences (2006) *Personal data for public good: using health information in medical research*:

<http://www.acmedsci.ac.uk/download.php?file=/images/publication/Personal.pdf>

8) Recruitment of patients to multicentre ovarian cancer screening (United Kingdom)

Identifying potential participants is the first and potentially one of the most important steps in clinical research. Were the LIBE rapporteur's amendments to be accepted, the process of identifying and inviting people to take part in a study is likely to become prohibitively difficult, particularly where large numbers of participants are required.

People with ovarian cancer have a poor survival rate and are often diagnosed in advanced stages of the disease. Improved diagnostic tools can assist earlier diagnosis that ultimately leads to increased patient survival and quality of life. The UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) was designed to investigate the efficiency of different screening techniques for ovarian cancer.

The recruitment process to this study shows the importance of access to patient data. During the course of the UKCTOCS study, more than 200,000 postmenopausal women without ovarian cancer were recruited out of over 1.2 million women who were initially contacted by post. Invites were sent to potential participants who were routine patients in participating trial centres and this recruitment strategy was approved by an ethics committee. Only 32 of the women (this is 0.0026%) raised concerns about being contacted, which demonstrates the enthusiasm of patients for participation in clinical trials.

Were the LIBE rapporteur's amendments adopted, specific consent would be needed to identify and contact the 1.2 million eligible women, even before inviting them to take part in the study itself. This would make recruitment for important large-scale studies such as the one described extremely difficult to conduct.

More information on this can be found at:

Menon et al. (2008) *Recruitment to multicentre trials—lessons from UKCTOCS: descriptive study.*
BMJ 2008;337:a2079

<http://www.bmjjournals.org/cgi/content/full/337/bmj.a2079>

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