

**Cancer Research UK Response to the Ministry of Justice Call for Evidence on the Review of the Balance of Competences between the United Kingdom and the European Union: Information Rights**

**June 2014**

**Cancer Research UK position on the use of patient data in research**

Access to patient data is essential for cancer research and, ultimately, for saving lives. The information held about patients in their medical records, in cancer registries and other databanks can be used to research the causes of cancer, monitor survival rates, study the effectiveness of treatments and interventions such as screening, and identify appropriate participants for clinical trials. In other words, patient data holds the key to medical progress.

Patient data has the potential to deliver huge public benefit, but it is also often highly sensitive for the individuals concerned. Cancer Research UK works on promoting a regulatory and governance framework which enables researchers to access the lifesaving data they need, while also ensuring that patient confidentiality is protected. The Data Protection Regulation must strike a crucial balance between protecting personal confidentiality whilst enabling life-saving research.

**What evidence is there that proposals for a new EU Data Protection Regulation will be advantageous or disadvantageous to individuals, business, the public sector or any other groups in the UK?**

If implemented in its current form the new EU Data Protection Regulation would seriously impact on medical research in the UK. The European Parliament position that emerged from amendments made by the European Parliament Civil Liberties, Justice and Home Affairs (LIBE) Committee would make much research involving personal data at worst illegal, and at best unworkable.

The original draft Regulation proposed by the European Commission struck a crucial balance, setting out a proportionate mechanism for protecting privacy, whilst enabling health and scientific research to continue. It included a requirement for specific and explicit consent for the use and storage of personal data, but provided an exemption from consent for research, subject to certain safeguards in Article 83.

The LIBE Committee's amendments to Articles 81 and 83 – now adopted by the European Parliament – very significantly reduce the scope of the exemption for research. The use of personal data in research without specific consent would be prohibited or become impossible in practice.

Consent is a crucial ethical principle and researchers will seek consent or use anonymous data where possible. However, it is not always feasible to seek consent, particularly where it is required to be specific and explicit. Where this type of research does take place, it is subject to ethical approval and strict confidentiality safeguards, and the identity of individuals is often masked.

If implemented in its current form the Regulation would put at risk significant European investments in genetics, cohort studies, biobanks, disease registries and the use of routinely collected data. This would

undoubtedly damage progress towards understanding society, health, and disease that delivers real patient benefit.

We hope that the position of the European Council and subsequent dialogue talks can recalibrate the balance between protecting privacy and enabling research that has now been lost.

These are just a few examples of lifesaving studies which would be severely impacted by the EU Data Protection Regulation:

### **Concord Studies<sup>1</sup>**

CONCORD-2 is a study which compares cancer survival in different countries. It will allow us to look at how cancer affects countries across the world and allows policy makers to look at how our health service can be improved to deliver better cancer outcomes.

### **Million Women Study<sup>2</sup>**

The Million Women Study is a national study of women in the UK over 50. The study is investigating a wide range of different factors and how they affect women's health. It has already produced important findings about how HRT and hysterectomies can impact on cancer risk.

### **UK Collaborative Trial of Ovarian Cancer Screening (UKCTOCS)<sup>3</sup>**

UKCTOCS is investigating the possibility of screening for ovarian cancer. More than 4,000 women die from this disease each year and we know that the earlier cancer is diagnosed, the more likely treatment will be successful. Researchers contacted women to invite them to take part having accessed their identifiable data to check that they were eligible. More than a million women were contacted – only 32 complained about being asked if they would like to participate in the study. Preliminary results have already been published and it looks like screening could help detect the disease early, although we do not yet know if it could reduce deaths.

### **The International Cancer Benchmarking Partnership (ICBP)<sup>4</sup>**

The ICBP is a unique international partnership looking at variation in cancer survival between countries. We know that the UK doesn't have the best survival in the world, but we do not fully understand why. This is the key question which the ICBP is addressing. The ICBP relies on high precision data because, in order to compare ourselves to other countries, we need a detailed understanding of what is happening in the UK. The answers the ICBP is giving us will help decide approaches to cancer treatment and policy in the future so that we can save the most lives possible.

We hope our comments are useful. For more information on our position on the European Data Protection Regulation, please see the Joint Statement which we are signed up to with other European non-commercial research organisations and academics.<sup>5</sup>

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<sup>1</sup> <http://www.lshtm.ac.uk/eph/ncde/cancersurvival/research/concord/index.html>

<sup>2</sup> <http://www.millionwomenstudy.org/introduction/>

<sup>3</sup> <http://www.instituteforwomenshealth.ucl.ac.uk/womens-cancer/gcrc/ukctocs>

<sup>4</sup> <http://www.cancerresearchuk.org/cancer-info/spotcancerearly/ICBP/>



If you would like to discuss our comments further please contact Catherine Castledine, EU Public Affairs Manager, on Catherine. Castledine@cancer.org.uk or on 0203 469 5129.

### **About Cancer Research UK**

Every year around 300,000 people are diagnosed with cancer in the UK. Every year more than 150,000 people die from cancer. Cancer Research UK is the world's leading cancer charity dedicated to saving lives through research. Together with our partners and supporters, Cancer Research UK's vision is to bring forward the day when all cancers are cured. We support research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. In 2012/13, we spent £351 million on research in institutes, hospitals and universities across the UK. The charity's pioneering work has been at the heart of the progress that has already seen survival rates in the UK double in the last forty years. We receive no government funding for our research.

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<sup>5</sup> [http://www.cancerresearchuk.org/sites/default/files/libe\\_report\\_joint\\_statement\\_january\\_2014.pdf](http://www.cancerresearchuk.org/sites/default/files/libe_report_joint_statement_january_2014.pdf)