

Tuesday, 27 January 2015 to Wednesday, 28 January 2015

## How do We Improve Health without Betraying Confidentiality within Current and Upcoming EU Regulations?

In the 2015 Annual Conference we will debate the tensions between confidentiality and transparency in health research. It will provide an opportunity to hear up to date information from experts involved, listen to differing viewpoints, particularly those of patients and patient groups whose voice must be central in this debate. It will also present opportunity to consider current solutions.

Tangible outcomes will be

1. Description and report on data protection arrangements in research across the EU through the EFGCP Research Ethics Committee survey
2. Debate on and development of a draft statement on secondary use of data in research
3. EFGCP report and recommendations that will be provided to those involved in the legislative process.

Progress in our understanding of the factors underpinning good health is leading us towards developing better treatments. Much of this advance is founded on the use of personal data, such as our health records. Without access to this data, medical progress would be seriously impeded and proposed restrictive access to clinical information poses a serious, immediate threat to research. There is a real danger we will sleepwalk into a position where we undermine health research designed to provide health care benefit.

This has been recognised within the discussions around the new EU Clinical Trial Regulations but it could be irreparably damaged by proposed Data Protection Regulations. While protection of privacy must be a central tenet of any legislation, some amendments will make vital research unworkable. The use of personal health data in research would become impossible in practice. This poses a significant risk to our health. Our conference will seek to strike a balance in answering the key questions.

Last update: 16 December 2014

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