

Clarifications of editorial content to the article:

“Big pharma mobilising patients in battle over drugs trials data”

Brussels, 22 July 2013 – the European Patients’ Forum (EPF) would like to provide some clarifications regarding the article released today on The Guardian’s website and entitled “[Big pharma mobilising patients in battle over drugs trials data](#)”. We denounce the accusation that “an army of patients groups” are being “mobilised by Pharma to lobby against plans to force companies to publish secret documents on drugs trials”.

On the contrary, EPF and our members, representing the interests of over 150+ million patients with chronic diseases, have consistently called for the publication of all results of all clinical trials, be they industry or publicly funded, in a timely manner, regardless of the outcomes. This is reflected in our [position on the Clinical Trials Regulations](#) with the European Commission and our extensive advocacy work in the European Parliament.

Our [engagement in the ‘ALLTrials campaign’](#) indicates also our unequivocal commitment to disclosure and transparency.

We are not aware of any *bona fide* patient group that would advocate another stance and would be interested to know which patient groups make up the ‘army’ being referred to in the article.

We strongly believe that any results – even of trials that ‘failed’ or produced unexpected or inconclusive outcomes – contribute to the totality of the evidence base on therapies, and can help target future research to where it is needed.

EPF further acknowledges the benefits of sharing raw data from clinical trials to enable researchers to revisit and reanalyse these data. This is in the interest of good science, patients, and the public. EPF therefore welcomes the recent initiative by the European Medicines Agency, to open a public discussion on how to best share data from clinical trials.

The EU clinical trials regulatory framework has been and will be with us for many years to come. This is why it is vital to get it right. The Regulation should be forward looking, in order to address the change and evolution in science, and also in the way science is done.

For more information please contact EPF Executive Director, Nicola Bedlington, at nicola.bedlington@eu-patient.eu.

The **European Patients' Forum (EPF)** was founded in 2003 to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

EPF currently represents 61 member organisations - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organisations. EPF reflects the voice of an estimated 150 million patients affected by various diseases throughout Europe.

EPF's vision for the future is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

The EPF strategic goals focus on areas such as health literacy, healthcare, patients' involvement, patients' empowerment, sustainable patients' organisations and health discrimination.

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