

IAPO Endorsement of the AllTrials Campaign

July 2013



Following approval at its May 2013 Governing Board Meeting, the International Alliance of Patients' Organizations (IAPO) is pleased to endorse the AllTrials campaign as an important step towards greater transparency and patient information. IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide. Our members are patients' organizations working at the local, national, regional and international levels to represent and support patients, their families and carers. IAPO has over 200 members which span over 60 countries and 60 disease areas and through its membership represents an estimated 365 million patients worldwide.

The publication of clinical trial results is vital in improving the quality of healthcare to patients. Without full access to the results of clinical trials, healthcare professionals and regulators cannot make informed recommendations on treatment options and patients are unable to make informed decisions on their healthcare. The publication of clinical trial results is critical to ensuring that patients have accurate information on treatments, their efficacy and their relative benefits versus risk.

Patient information is a core principle of patient-centred healthcare. To IAPO, accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about their healthcare. A key component of good quality patient information is that it is presented in an appropriate format. Therefore, it is essential that clinical trial results are published in a way that can be understood by patients and the general public.

IAPO strongly supports measures to increase transparency on clinical trials results, but this should not come at the expense of patient privacy. Where there are trials that are undertaken on small sample sizes, particularly in the development of orphan drugs, it is critical that patient privacy is protected and that all potentially identifiable information is removed prior to publication.

The publication of clinical trial results is a sensitive issue and needs the involvement of all stakeholders to facilitate openness and transparency. In particular, the patient perspective must be solicited to make sure that patient needs are met in relation to the protection of personal information and the presentation of clinical trials results.

IAPO looks forward to working with the AllTrials campaign towards greater transparency and patient care.