



## **One third of clinical trials run by America’s top research universities are in violation of a key transparency law, according to new report**

WASHINGTON, DC & BRISTOL, UK: {25 March 2019}, By law, since 2017, America’s top research universities had to post the results of 450 clinical trials. However, 31% of those trials are still missing results on the public registry, in violation of the FDA Amendments Act, according to the report released today via [www.altreteroute.com/clinicaltrials](http://www.altreteroute.com/clinicaltrials) by Universities Allied for Essential Medicines (UAEM) in partnership with TranspáriMED, a non-profit research advocacy group.

Timely clinical trial reporting helps researchers avoid creating duplicative studies and guards against fraud and reporting bias, in which scientists selectively publish “successful” results only. Clinical trial transparency accelerates medical progress for new treatments, improving understanding of treatment efficacy and safety, ultimately contributing to improved access to medicines and better health outcomes.

[Universities Allied for Essential Medicines](#) (UAEM), a global student-driven organization, is leading a campaign to push their own institutions to become the first research universities in the world to sign onto the [World Health Organisation \(WHO\)’s Joint Statement](#) on Clinical Trial Transparency, formally committing to meeting global best practices in medical research transparency.

“We advocate full transparency of which clinical trials are ongoing and ensuring all results are disclosed in a timely manner in accordance with the WHO Joint Statement on disclosure of results from clinical trials,” said Dr Tedros Adhanom Ghebreyesus, WHO’s Director-General. “This is consistent with the principal goal of medical research: to serve the betterment of humanity. In the case of clinical trials, full transparency on results advances both scientific understanding and timelines for product development and ultimately enables access to essential medicines. We would welcome Universities joining as signatories.”

Jackie Xu, UAEM Student Leader at Duke University shared, “ Universities play a key role in the world of scientific and clinical which is often funded through taxpayer-based dollars. Students and future alumni, like myself, are uniquely positioned to demand that the institutions that both *represent them* and that *they represent* to do better. I am proud that Duke University has been reporting at 100% compliance with FDA Amendments Act since 2017, but I hope Duke can take the next step forward and publically commit to clinical trials transparency with the WHO statement. This is a standard global practice. We have the obligation to at least fulfill this.”

The current list of violators includes major trial sponsors. For example, the academic institution sponsoring the most applicable trials, MD Anderson Cancer Center, has only reported 77% of due trials. Mayo Clinic (42%), UC San Francisco (37%), New York University (21%), and Columbia University (17%) perform even worse. While some universities continue to violate the Food and Drug Administration (FDA)'s 2007 and 2017 clinical trial transparency law requirements for research reporting, others have invested considerable resources into ensuring timely disclosure of trial results and retroactively publishing to clear backlogs of previously unreported trials.

Prior to 2015 the universities of Indiana, North Carolina Chapel Hill, Rochester, Pittsburgh and Yale had an extensive backlog of unreported trial results. They have since successfully cleared over 85% of their backlogs. Stanford (65 trials), Johns Hopkins (47), and Pittsburgh (45) posted most trial results.

An estimated 50% of all new medical innovations and technologies are developed by universities using taxpayer dollars via grants from the National Institutes of Health.

“As institutions with social missions, universities are morally bound to be transparent with their research outcomes especially when trials are publicly-funded in the first place” said Merith Basey, Executive Director of UAEM North America. “We are urging universities to step up their commitments by becoming the first universities worldwide to sign onto the WHO Statement, following in the footsteps of leading groups like Doctors without Borders, Drugs for Neglected Diseases Initiative and The Wellcome Trust.”

Without strong federal oversight on reporting requirements, advocates from UAEM and TranspariMED hope to shine a light on this practice and pressure universities to fulfill their missions that serve the public interest.

The launch of the report via (<http://www.altreroute.com/clinicaltrials/>) is a student-driven campaign that forms part of UAEM's larger push for a more equitable, transparent, collaborative and patient-centered biomedical Research and Development (R&D) system, in which university-driven clinical trials play an important role.

“Patients and taxpayers are paying a steep price while law-breaking companies and universities walk free. The FDA should start by enforcing the law by imposing fines immediately to prevent important medical discoveries from becoming lost forever,” said Dr. Till Bruckner, the founder of TranspariMED.

### **About UAEM and TranspariMED:**

**[Universities Allied for Essential Medicines \(UAEM\)](#)** is a global network of university students organizing on their campuses and beyond to ensure that publicly funded medicines is accessible and affordable for all, regardless of income. UAEM believes that Universities and publicly funded research institutions will be part of the solution to the access to medicines crisis

by promoting medical innovation in the public interest and ensuring that all people regardless of income have access to medicines and other health-related technologies.

**TranspariMED** is a global initiative that develops and promotes policy solutions to improve clinical trial transparency.

[www.altreroute.com/clinicaltrials](http://www.altreroute.com/clinicaltrials), a microsite and report launched today by UAEM in conjunction with TranspariMED, provides performance data for the 40 major U.S. universities that have sponsored the largest number of trials subject to the FDA Amendments Act of 2007 (FDAAA).

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