Publicly-funded research: too opaque!

Clinical trial registries and availability of trial results are essential elements in the transparency of clinical research (1,2). How are publicly-funded clinical research organisations satisfying this need for transparency?

Insufficient transparency. A team of authors investigated whether the major non-commercial funders of clinical trials worldwide (public or private foundations) were applying the World Health Organization (WHO) recommendations on the transparency of clinical trials (1). These recommendations are similar to various other international initiatives taken since 2000, mainly concerning: registration of clinical trials before they are initiated, including a description of the protocol; publication of the results; and access to individual patient data (1,2). The authors checked with the funding organisations whether they had policies concerning this issue, what they consisted of, and whether adherence was monitored (1).

The results are not brilliant. Among the top 18 public organisations or private foundations financing clinical trials, only 9 required registration of all trials, 8 required publication of at least a summary of the results, including 4 within the allotted time frame of 12 months, and only 2 required access to individual patient data (1).

France in last place. The most transparent organisations were those of the United States, Britain, Canada, Germany and the European Commission. The French National Institute for Health and Medical Research (Inserm) and the National Centre for Scientific Research (CNRS) came in last, along with the Chinese Ministry of Health (1).

France's CNRS at odds with statistics? The shortcomings of the French organisations do not stop there. On 17 April 2018, the CNRS published a triumphant press release applauding the results of a clinical trial of *forigerimod* in lupus (3). Paradoxically, on the same day, the share price of Immu-Pharma, the company that holds the commercial rights to this drug developed by the CNRS, fell by 77% (4). In fact, stock market analysts were not mistaken. The efficacy results for *forigerimod* were not statistically significant, a "detail" that had apparently escaped the CNRS which had appeared surprisingly enthusiastic.

These facts show that Inserm and CNRS are not up to the mark when it comes to clinical research transparency, whereas publicly-funded organisations, they should be setting an example.

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Selected references from Prescrire's literature search

- **1-** DeVito NJ et al. "Noncommercial funders' policies on trial registration, access to summary results, and individual patient data availability" *JAMA* 2018; **319** (16): 1721-1723.
- **2-** Prescrire Editorial Staff "Clinical trials registries: towards improved access to therapeutic data" *Prescrire Int* 2008; **17** (98): 256-259.
- **3-** CNRS "Efficacité clinique démontrée pour le Lupuzor°, premier traitement contre le lupus sans effets secondaires" Press release 17 April 2018: 2 pages.
- **4-** "ImmuPharma puts on very brave face after lupus drug flop" *Scrip* 27 April 2018: 18.

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