

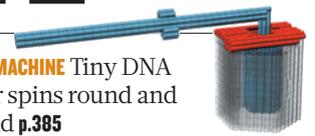
THIS WEEK

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Safety first

It is worrying that US government departments are unable to divulge basic data on research projects involving human subjects. Such data should be publicly available to ensure volunteers' safety.

“Your safety is our priority.” It’s difficult to visit a sports stadium, travel on an aircraft or even head to the cinema these days without being told that someone, somewhere, is watching out for you. So why do some systems that are set up to protect the volunteers who participate in scientific research seem so inadequate?

It’s not as if we haven’t been warned about what can happen when supervision and scrutiny are lax. In 2010, the US Presidential Commission for the Study of Bioethical Issues was tasked with a sobering mission. A series of horrifying medical experiments on Guatemalan citizens — some intentionally infected with syphilis — in the 1940s had recently come to light. President Barack Obama asked the commission to determine whether such an atrocity could still happen today, and to evaluate the protections in place for all who participate in human-subject research funded by the US government.

The commission soon ran into a problem: a portrait of the current system was difficult to paint. Some government departments did not have ready access to essential data for identifying and tallying federally funded projects involving human subjects. More than six months after the commission asked for them, some departments were still unable to provide basic information, such as a list of all such projects, the number of participants involved and the location of the work.

When it reported its findings in 2011, the commission concluded that current regulations probably protect research participants from unethical treatment. But it could not say so with certainty: “Because of the currently limited ability of some governmental agencies to identify basic information about all of their human subjects research, the Commission cannot say that all federally funded research provides optimal protections,” the report concluded.

To improve the situation, and to help to secure the protection of all involved, the commission made a simple request. Any federal department or agency that supports human-subject research should make a core set of data publicly available, listing the research title, investigator, location and funding. The Department of Defense quickly complied, but some agencies still have not. That is not good enough. Although the bioethics commission cannot compel agencies to collate and gather this information, if these agencies are to preserve public trust and ensure future research, then they should all do so.

The system that oversees human-subject research in the United States is already secretive at too many levels. For example, the ethics committees that assess risk and approve projects — institutional review boards — deliberate in private. Although there are guidelines on the types of expert who should sit on the boards, the guidelines are toothless because there is no independent system to check that they are followed. In 2009, investigators from the Government Accountability Office reported that they had been able to register a bogus ethics committee with the Department of Health and Human Services.

It is true that many federally funded medical trials are logged on the ClinicalTrials.gov website. But sponsors are not forced to register early, phase I studies, and the database extends to non-medical projects.

Officials and government agencies are keen to talk up the benefits of gathering big data. Well, now they need to cough up some information themselves. And there is more to providing these details than mere box-ticking. A reliable map of where research is taking place and what projects are under way allows researchers — and members of the public — to identify gaps and redundancies. It could flag up populations of research participants who are being under- or over-sampled, and studies that are being conducted on populations that may not receive the benefit of the results.

Despite the struggle to obtain useful data, the bioethics commission’s report was able to estimate that the government funded more than 55,000 projects involving human subjects in fiscal year 2010. Most of those were medical studies.

It’s time for the system to give a little back to the many thousands of volunteers who help researchers to advance these studies, sometimes at risk to themselves — by lifting the veil of secrecy that limits oversight of such risks. Making the effort to fulfil the commission’s recommendation is a good way for those in charge to start. ■

“The system that oversees US research on human subjects is secretive at too many levels.”

Generation game

A Nature special issue takes on the world of tomorrow — and the decisions shaping it today.

How do we get to the future? As the old joke goes: well, I wouldn’t start from here. Perhaps the greatest trick that the film director George Lucas ever pulled was to set his Star Wars series not in the future, but a long time ago. Lucas’s emblematic take on once-upon-a-time introduced each film as entirely unconnected in space and time to the present day. Everybody on screen was long dead. Their lives and troubles and loves and hates were dust. The tales of heroism and noble deeds were essentially myths.

Much science fiction does the opposite. It takes what we have now and spins it forward. Or it picks a destination and charts a course. Occasionally, the two narrative devices collide awkwardly, and present-day humans discover some futuristic technology, which they use to change their own path. But most of the time, even tales of aliens and interplanetary travel are presented as a consequence