

Payments by agency by year (note some agencies have redacted totals so this is less than true total)

FY2010: \$18,791,296.99

FY2011: \$22,444,175.55

FY2012: \$26,879,545.30

FY2013: \$30,462,168.86

FY2014: \$35,450,481.94

The four NIH agencies included but with redacted totals:

NCATS National Center for Advancing Translational Sciences

NIAAA National Institute on Alcohol Abuse and Alcoholism

FIC Fogarty International Center

NCCAM National Center for Complementary and Alternative Medicine

- NCCAM is now called NCCIH, National Center for Complementary and Integrative Health

The National Institute of Health is resisting every effort to bring transparency to millions of dollars in royalty payments its research scientists receive every year in addition to their salaries. The U.S. Department of Health and Human Services began developing guidance for collecting and publishing royalty data from NIH researchers over twenty years ago. This data, however, is not publicly available.

NIH is still not disclosing information about what companies are using patents developed at the NIH, and which researchers are getting paid for them. OpenTheBooks.com sued the agency to release these documents under a Freedom of Information Act request, but documents received so far are highly redacted and over a decade old.

Patent Payouts

The National Institute of Health, part of the U.S. Department of Health and Human Services, is the [largest](#) biomedical research agency in the world. NIH grants over [\\$32 billion](#) in funding to research institutions around the world, and employs [thousands](#) of scientists to conduct research in-house.

When an NIH employee makes a discovery in their official capacity, the NIH [owns](#) the rights to any resulting patent. These patents are then licensed for commercial use to companies that could use them to bring products to market. Employees are listed as inventors on the patents and receive a share of the royalties obtained through any licensing, or “technology transfer,” of their inventions.

Essentially, taxpayer money funding NIH research benefits researchers employed by NIH because they are listed as patent inventors and therefore receive royalty payments from licensees.

Researchers could be involved in experiments using technology they invented, furthering the application and commercial viability of that technology, which may or may not be in the public's best interest.

Inventors receive the first \$2,000 collected from a licensee. Next, they receive 15 percent of royalties above \$2,000 and up to \$50,000. Finally, they receive 25 percent of royalties in excess of the first \$50,000 collected each year. Each inventor cannot receive more than \$150,000 in royalty payments for a calendar year.

Understanding Conflict of Interests: Patients

The HHS came under fire in 1999 when a young man died while undergoing experimental gene therapy treatment at the University of Pennsylvania for an NIH Office of Biotechnology Activities clinical trial.

An investigation showed [many](#) administrative failures and irregularities leading up to his death, including a financial conflict of interest; a principal investigator owned shares in a company that would benefit from the experimental technology.

In response to the tragedy and broader concerns with ethics in clinical trials at the agency, in 2000 then-HHS Secretary Donna Shalala [pledged](#) reforms to better protect patients involved in research experiments.

HHS guidance released in 2001 [outlined](#) steps that had to be taken by the agency to achieve these goals.

One reform enhanced transparency in researchers' financial conflicts of interest—if a researcher stood to financially gain from experiments involving humans, their patients had to know.

In 2005 an explosive investigation by the Associated Press [found](#) the NIH had not yet provided these financial disclosures to patients. Through Freedom of Information Act requests, AP found over 900 NIH researchers collected \$8.9 million in 2004.

AP also discovered that 51 NIH royalty recipients were then working on experiments involving inventions for which they were being paid.

[Among](#) those 51 was Anthony Fauci, then- and current director of the National Institute of Allergy and Infectious Diseases, who had received \$45,072.82 between 1997 and 2004 for a patent license on an experimental AIDS treatment.

At the time, Fauci expressed confusion and frustration regarding conflict of interest disclosure at NIH, noting he donated all proceeds from the royalties to charity.

Shortly after AP filed the FOIA request in 2004 for the royalty payments NIH scientists receive from patents, NIH released new [guidelines](#) on such financial disclosures.

Understanding Conflict of Interests: The Public

Patients involved in clinical trials can now benefit from information regarding a researcher's potential conflict of interests.

But the public that funds this research, and the lawmakers that provide oversight to these agencies, are in many ways still in the dark.

The U.S. Government Accountability Office released a [report](#) in 2020 titled “NIH Should Publicly Report More Information about the Licensing of Its Intellectual Property.”

The report identified 4,446 U.S. patents owned by HHS, but focused only on patents that contributed to the development of drugs approved by the FDA.

In total, 93 NIH patents contributed to 34 FDA-approved drugs. The NIH granted 32 licenses to pharmaceutical companies based on these patents, which generated about \$2 billion in royalty payments to the agency between 1991-2019.

GAO highlighted the importance of transparency in maintaining trust and improving understanding of the research process.

Because the HHS funds billions of dollars in research a year, primarily through NIH, there are concerns regarding how private companies benefit from this research, particularly regarding how much they charge for therapies created using taxpayer funds. There are also concerns related to how the FDA, another HHS agency, approves treatments that NIH scientists contribute to.

Licensing and royalty transparency could help policymakers and the public understand the complicated nexus between federal research and regulatory agencies and the private sector.

GAO made several recommendations to improve transparency, [including](#) to “publicly report information [regarding licensing outcomes and impacts] in an accessible and searchable format to the maximum extent possible.”

The NIH responded by listing all of its “active U.S. patents” on a webpage. [Thousands](#) of patents are listed, broken out by institute, but licensee, inventor, and royalty information are not included.

Agency officials also told GAO they “are working to deploy a new enterprise technology transfer system that will allow them to publish additional information on active commercial licenses,” but have not yet.

Opening the Books on NIH Royalty Payments

Over the past 20 years the HHS has proven it is in no rush to make financial disclosures at the agency more transparent.

In September 2021 OpenTheBooks.com filed FOIA requests with NIH [asking](#) for a complete list/database of all personal royalties paid to current and former National Institutes of Health employees for work done while they were federally employed.

We specified that the list/database should include the royalty recipient's name, the amount of the royalty, the reason for the royalty, the date the royalty was paid, and the name of the entity paying the royalty.

NIH failed to comply with this request, so we partnered with Judicial Watch to sue for these documents in October 2021.

In response to the lawsuit, NIH began producing approximately 300 pages in royalty payments a month, starting in February 2022.

The documents we have received so far have been heavily redacted, only revealing most (but not all) of the names of the researchers receiving payments, how many payments they received, and how much money each NIH institute has collected in royalties.

According to NIH Freedom of Information Officer Karen E. Lampe-S, redactions were made under three exemptions:

- The Federal Transfer and Technology Act, 15 USC 3710a(c)(7)(A), prohibits federal agencies from disclosing commercial or financial information, including royalty information, obtained from parties participating in technology transfer with Federal Agencies.
- Protecting disclosure trade secrets and commercial or financial information that is privileged and confidential.
- Permitting the withholding of privacy information, the release of which would constitute a clearly unwarranted invasion of personal privacy.

The NIH redacted all information regarding how much researchers are being paid and what licensees are paying these royalties. We asked for all documentation up to 2020 or later, but the first documents we received so far, about 1,200 pages, are from October 2009 to September 2014.

While most pages were machine-readable, several pages documenting the frequency of payments were not, and so could not be included in our analysis.

Still, we can make some interesting observations based on the data we do have.

During the time period covered in these documents, **October 2009 to September 2014**, NIH inventors received over \$134 million in royalty payments. Over **1,600** different scientists were named as personally receiving royalty payments during this time. More names and payment amounts were redacted, however, and could not be included in these counts.

The top five scientists receiving royalty payments and the institutes they were affiliated with are as follows. Only Ira Pastan is still employed with NIH:

- 1 Robert Charles Gallo, National Cancer Institute, 271 payments
- 2 Ira Pastan, National Cancer Institute, 250 payments
- 3 Mikulas Popovic, National Cancer Institute, 191 payments
- 4 Flossie Wong-Staal, National Cancer Institute, 190 payments
- 5 Mangalasseril Sarngadharan, National Cancer Institute, 188 payments

*Note these only indicate frequency of payments. There is no way to know the payment amount because of how these documents are redacted. Frequency numbers may also be under-counted due to irregularities in machine-readability of documents.

Anthony Fauci, perhaps the most famous NIH employee and the highest-salaried person in the federal government, received 23 payments. Francis Collins, NIH director from 2009-2021, received 14.

21 of NIH's 27 institutes and centers reported royalty income, along with the FDA. The FDA is not an NIH agency but formed a joint council with the NIH in [2010](#) to strengthen collaboration. The institute reporting the most income from royalty payments during this time is the National Cancer Institute, with \$112,976,379. Four institutes reported income that was redacted.

While the documents we have received so far are illuminating, we need more information to understand the full ecosystem of royalty payments and federally-funded scientific research. We will be regularly updating our readers with new findings as we collect more documents.