

Ad Hoc Group Weekly Round Up – October 15, 2018

Each week, the Ad Hoc Group Weekly Round Up will feature hashtags and/or tweets (follow us at [@fundNIH](#)) suggested by members of the National Institutes of Health (NIH) advocacy community. We encourage all readers who are active on social media to use these messages, and we welcome suggestions from the community for future issues of the Weekly Round Up. Here is this week's featured tweet:

Biophysical Society @BiophysicalSoc

"BPS members [@DrVidSiva](#) and [@Iscairns18](#) share their experiences attending last month's Rally for Medical Research and [@GoldGooseAward](#) ceremony:

[@RallyForNIH](https://www.biophysics.org/blog/bps-members-rally-for-medical-research-attend-golden-goose-award...#RallyMedRes)"

1. NIH Request for Information on New Data Sharing Policy

The NIH Oct. 10 issued a [request for information](#) (RFI) on [proposed provisions](#) to serve as a foundation for a new data management and sharing policy for NIH-funded research. Among the topics NIH seeks input on are: the definition of scientific data; required elements for data sharing and management plans; and the optimal timeline for implementing a new policy. NIH Director Francis Collins, MD, PhD, [expressed](#) his personal enthusiasm for the RFI via Twitter. A [blog post](#) by NIH Associate Director for Science Policy Carrie Wolinetz, PhD, gives more background on the RFI and provides information on a Nov. 7 [webinar](#) on the proposed provisions. Comments on the RFI are due to the NIH by Dec. 10.

2. STAT Interview on Changing Landscape of Science in China

STAT Oct. 15 [published an interview](#) with Director of the McGovern Institute for Brain Research at the Massachusetts Institute of Technology (MIT), Robert Desimone, PhD, including questions about the changing research landscape in China. MIT's Institute for Brain Research also has labs in three Chinese universities. In the interview, Dr. Desimone discussed various issues in the Chinese research enterprise, including: regulatory burden; recent increases in investments in Chinese R&D; the use of gene editing technology; data fabrication; and intellectual property theft.

3. NIH Concludes Protecting Human Research Participants Training Course

In an [Oct. 10 blog post](#), the NIH Office of Extramural Research reminded institutions that as of Sept. 26, NIH will no longer offer the Protecting Human Research Participants (PHRP) course. The post notes that "although similar courses are available elsewhere, such courses are not affiliated with or endorsed by NIH ... [and] institutions seeking to fulfill the requirement for education in the protection of human research will need to use another training program or develop a program to meet the requirement."

4. Director's Blog: Using Frogs to Tackle Kidney Problems

In an [Oct. 11 blog post](#), NIH Director Francis Collins, MD, PhD, discusses recently published NIH-funded research using frog embryonic skin cells to better understand human kidney function. In using an animal model, the researchers were able to study "hair-like projections called cilia" on the surface of frog skin cells, which are also found in human kidneys to sense fluid flow. The researchers hope to better understand "how abnormalities in the formation or

function of cilia may lead to the formation of kidney cysts, a condition that can progress to kidney failure.”

5. NIH Programs Connect Gene Variants to Health and Disease

An [Oct. 12 NIH news release](#) details the important contributions of two NIH programs to create a common language and foster data sharing in genomics, leading to a better understanding the role of gene variants in human disease. The programs ClinGen and ClinVar “address a major barrier to incorporating genomic medicine into health care, which is a lack of evidence about the relationship between gene variants and diseases.” National Human Genome Research Institute Director Eric Green, MD, PhD, noted that “through the work of ClinGen and ClinVar, more than 730 researchers, clinicians and curators from 230 institutions have been working together to standardize the evaluation of genes and genomic variants implicated in human disease.”

6. New NIH Videos Provide Tips for Grant Applicants

An [NIH blog post](#) from the Office of Extramural Research (OER) describes a new series of videos aimed to assist in the grant application process. Topics include how to: access application forms; ensure your application is a good fit for an announcement; and make an important final check of your application after submitting.

7. NIH Blog Post: Delineating Roles of Fellows and Trainees in NIH-Sponsored Clinical Trials

An [Oct. 12 blog post](#) from the Office of Extramural Research (OER) encourages National Research Service Award (NRSA) grant recipients to undertake training in clinical research, including the conduct of clinical trials. The post suggests that “fellows and trainees can gain experience in the wide variety of research skills specific to clinical trials including, but not limited to: developing a clinical trial protocol; applying the principles of informed consent and requirements for human subjects research; learning about random assignment of participants to different intervention arms; analyzing trial endpoints; and/or implementing quality control standards.”

8. NIH Online Clinical Research Courses are Now Open

The NIH's [Office of Clinical Research](#) is [offering](#) free, self-paced online clinical research courses. A course on the [Introduction to the Principles and Practice of Clinical Research](#) “trains participants on how to effectively and safely conduct clinical research,” including study design, measurement, statistics, ethical, legal, monitoring, and regulatory considerations, preparing and implementing clinical studies, additional study designs, and more. Another course on the [Principles of Clinical Pharmacology](#) covers the fundamentals of clinical pharmacology as a translational scientific discipline,” including pharmacokinetics, drug metabolism and transport, drug therapy in special populations, assessment of drug effects, drug discovery and development, pharmacogenomics and, pharmacotherapy.” Both courses are available through June 2019.

9. *Nature*: Japan Set to Allow Gene Editing in Human Embryos

David Cyranoski Oct. 3 [reported in *Nature*](#) that an expert panel representing Japan's health and science ministries has issued draft guidelines to permit the use of gene editing tools on human embryos for research. The proposal, which is expected to go into effect next year, is currently open for public comment.

Upcoming Hill Briefings and Events

10. Panel Study of Income Dynamics 50th Anniversary Reception – Oct. 18

Please join the Panel Study of Income Dynamics (PSID) in celebrating its 50th anniversary during an Oct. 18th reception. The event will take place at the Newseum from 6:30 – 9pm. Please RSVP to pathall@umich.edu and see the attached flyer for additional details.

11. NIH Webinar on Data Sharing Proposed Provisions – Nov. 7

The NIH [will host a webinar](#) for the Request for Information (RFI) on Proposed Provisions for a Draft NIH Data Management and Sharing Policy on Wednesday, Nov. 7 from 11:30am-1pm.

12. NASEM: Meeting on Preventing Sexual Harassment in Academia – Nov. 9

The National Academies of Science, Engineering, and Medicine (NASEM) will [convene leaders](#), including “academic leaders, Title IX and diversity officers, ombudsmen, researchers in sexual harassment, and leaders from professional societies, foundations, and federal agencies, to discuss strategies and share promising practices” to discuss sexual harassment in academia. The meeting will be held Nov. 9, 2018, from 9:00am – 5:00pm at the National Academies in Washington DC, and will focus on developing strategies on how to prevent sexual harassment in academia.

13. Learn Serve Lead – Nov. 2-6, 2018

Learn Serve Lead 2018 - the AAMC Annual Meeting - is open for registration. The Nov. 2-6 event takes place in Austin, Texas, and will draw 4,500-plus attendees including a wide range of stakeholders. In addition to [four plenary sessions](#), including Grit author and researcher Angela Duckworth, PhD, and civil and women’s rights leader Anita Hill, JD, there are more than 130 concurrent sessions. Some of the slated sessions include:

- Improving Population Health Through Learner-Engaged Research
- Rightsizing Research Infrastructure
- Achieving Health Equity through Research: Innovations From NIMHD-Funded Science
- Unhealthy Politics: The Battle over Evidence-Based Medicine

[Registration](#) is available online through Thursday, Nov. 1.

Please Note: If you have information of interest to the NIH advocacy community that you would like to share with the Ad Hoc Group, please forward it to Christa Wagner at chwagner@aamc.org or Tannaz Rasouli at trasouli@aamc.org.