

Finding Historical Records at the National Institutes of Health

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Summary. This paper provides a guide to finding historical records of the National Institutes of Health (NIH), the US biomedical research agency funded by the federal government, and one of the world's largest research funding bodies. Such records are important to an understanding of the development of medicine and biomedicine after the Second World War, yet they can be difficult to find in the organizational maze that is the NIH. This article provides information on where records might be found, the ways in which such records might be obtained, and how the NIH manages the vast quantity of records it produces.

Keywords: National Institutes of Health; records; archives; access; preservation; destruction

The recent decision of the National Institutes of Health (NIH) to downsize its Office of History will make it more difficult for historians to gain access to the historical records of the NIH.¹ The Office was founded in 1986, and for the past 29 years one of its functions has been to facilitate access to such records, not always an easy task given the size and complexity of the organisation, and the sometimes parlous state of its record keeping.² Behind the scenes, the Office also has worked to preserve historical documents and artefacts, support research on the history of NIH, and provide historical interpretations of NIH activities to a range of audiences via a variety of media. However, with funding problems caused by the 2013 budget cuts known as the sequester, such activities have been reduced, and it is not clear how much help the Office may be able to provide historians in the future, assuming it survives

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¹Many of the citations in this article make references to NIH and other websites. All websites were checked for access (26 March 2015) shortly before this article went to press. Websites come and websites go, and in time it is likely that some of these links will no longer work. Some NIH websites will be preserved at the Internet Archive (cited in Online Sources, paragraph 10 below), others may be found by using an internet search engine.

²For a history of the office up to the retirement of its first director see C. Hannaway, 'Inventing the Office of NIH

History', in C. Hannaway, ed., *Biomedicine in the Twentieth Century: Practices, Policies, and Politics* (Amsterdam: IOS Press, 2008), 1–7. For an account of the tenure of its second director, Robert Martensen, see David Cantor, *Office of History, National Institutes of Health. Mission, Goals, Challenges. Overview Report to the Advisory Committee to the DDIR, NIH* (Bethesda, MD: Office of History, National Institutes of Health, 15 October 2012).

at all. Given this situation, this paper is intended to provide a guide to locating NIH historical records that will be publicly available whatever the eventual fate of the Office.

The organization that came to be called the NIH can be traced back to a hygienic laboratory established on Staten Island in 1887, the child of concerns about immigrants, immigrant diseases and their effect on native-born Americans.³ It moved to Washington, DC in 1891, and its focus broadened to cover a wider range of public health problems and scientific disciplines and approaches.⁴ However, until the 1940s it was a relatively small body, dwarfed by US philanthropic and industrial funders of biological and medical research, and a sideshow on the international scene. All this changed after the Second World War, when the NIH—now based in Bethesda, outside of Washington, DC—rapidly overtook US industrial and philanthropic support of what came to be called biomedicine, and emerged as the world's leading funder of biomedical research.⁵ In recent years, its primacy has been challenged, industrial support for biomedical research has come to overshadow that of the NIH, and commentators have argued that the current trajectory of NIH funding is unsustainable, and that there has been an increasing mismatch between the demand for research dollars and the supply.⁶ However, the NIH remains one of the largest sources of funding

³Victoria A. Harden, *Inventing the NIH: Federal Biomedical Research Policy, 1887–1937* (Baltimore, MD: Johns Hopkins University Press, 1986). David M. Morens, Victoria A. Harden, Joseph Kinyoun Houts, Jr. and Anthony S. Fauci, *The Indispensable Forgotten Man. Joseph James Kinyoun and the Founding of the National Institutes of Health* (Bethesda, MD: US Department of Health and Human Services, National Institutes of Health, National Institute of Allergy and Infectious Diseases, August 2012).

⁴For other publications that touch on the history of NIH before the late 1940s see: Alan M. Kraut, *Goldberger's War: The Life and Work of a Public Health Crusader* (Boston: Hill & Wang, 2003). Leo B. Slater, *War and Disease: Biomedical Research on Malaria in the Twentieth Century* (Rutgers University Press, 2009). David Cantor, 'Le National Cancer Institute: problème d'une intervention fédérale contre le cancer dans l'Amérique du début du XXe siècle', in Didier Foucault, ed., *Lutter contre le cancer (1740–1960)* (Toulouse: Éditions Privat, 2012), 329–58. David Cantor, 'Radium and the Origins of the National Cancer Institute', in Hannaway, ed., *Biomedicine in the Twentieth Century*, 95–146.

⁵In addition to the secondary literature cited elsewhere in this article see: Donald C. Swain, 'The Rise of a Research Empire: NIH, 1930 to 1950', *Science*, 14 December 1962, 138, 1233–7; G. Burroughs Mider, 'The Federal Impact on Biomedical Research', in John Z. Bowers and Elizabeth F. Purcell, eds, *Advances in American Medicine: Essays at the Bicentennial*, 2 vols (New York: Josiah Macy, Jr., Foundation, 1976) II, 806–71; Ronald Hamowy, *Government and Public Health in America* (Cheltenham, & Northampton, MA: Edward Elgar, 2007), esp. ch. 4; Roger L. Geiger, *Research and Relevant Knowledge: American Research Universities since World War II* (New York: Oxford

University Press, 1993), 179–85 and *passim*; Robert Cook-Deegan and Michael McGeary, 'The Jewel in the Federal Crown? History, Politics, and the National Institutes of Health', in Rosemary Stevens, Charles E. Rosenberg and Lawton R. Burns, eds, *History and Health Policy in the United States: Putting the Past Back In* (New Brunswick, NJ: Rutgers University Press, 2006), 176–201; John Kastor, *The National Institutes of Health, 1991–2008* (Oxford: Oxford University Press, 2010); Daniel S. Greenberg, *The Politics of Pure Science* (Chicago: University of Chicago Press, 1999); Daniel S. Greenberg, *Science, Money, and Politics: Political Triumph and Ethical Erosion* (Chicago: University of Chicago Press, 2001); Jean-Paul Gaudillière, *Inventer la biomédecine: la France, l'Amérique et la production des savoirs du vivant (1945–1965)* (Paris, La Découverte, 2002); Adele E. Clarke, Laura Mamo, Jennifer Ruth Fosket, Jennifer R. Fishman and Janet K. Shim, eds, *Biomedicalization: Technoscience, Health, and Illness in the U.S.* (Durham, NC: Duke University Press, 2010).

⁶A 2010 study published in *JAMA* suggested that industry accounted for 58% of all US spending on biomedical research, followed by NIH (27%), state and local governments (5%), and private not-for-profit support (4%). E. Ray Dorsey, Jason de Roulet, Joel P. Thompson et al., 'Funding of US Biomedical Research, 2003–2008', *JAMA*, 2010, 303, 137–43. For debates over the role of the private sector see Hamilton Moses III and E. Ray Dorsey, 'Biomedical Research in an Age of Austerity', *JAMA*, 2012, 308, 2341–42; Gordon H. Sun, Jeffrey D. Steinberg and Reshma Jaggi, 'Funding for Biomedical Research', *JAMA*, 2011, 309, 1228–9; Hamilton Moses III and E. Ray Dorsey, 'Funding for Biomedical Research—Reply', *JAMA*, 2013, 309, 1228–9; Bruce Alberts, Marc W. Kirschner, Shirley Tilghman and Harold Varmus,

for medical research in the world, supporting a vast range of activities across the spectrum of biomedicine, at numerous locations in the USA and across the globe.

The postwar history of the NIH is thus the story of the creation of an immense organization that has helped to drive the development of biomedical research as well as countless drugs, devices, procedures, and other medical and biomedical technical developments. While the NIH often itself sees its history as a story of a series of particular (sometimes spectacular) discoveries and innovations (Figure 1), its records are also central to an understanding of the infrastructures that supported and shaped postwar biomedicine, efforts to cultivate public support for biomedicine (in Congress, among advocacy groups, and through the media), federal policy towards numerous health problems, human subjects research, the various disciplinary and professional fields that make up biomedicine, and the enormous range of instruments, tools and practices that biomedical scientists have deployed since the 1940s.⁷ It is impossible in a few short introductory paragraphs to do justice to the

'Rescuing US Biomedical Research from its Systemic Flaws', *Proceedings of the National Academy of Sciences*, 22 April 2014, 111, 5773–7; Thomas Kelly and Kenneth Marians, 'Rescuing US Biomedical Research: Some comments on Alberts, Kirschner, Tilghman, and Varmus', *Proceedings of the National Academy of Sciences*, 1 July 2014, 111, E2632–E2633. For discussions of the complex relationship between NIH and the rise of commercial biotech see Nicolas Rasmussen, *Gene Jockeys: Life Science and the Rise of Biotech Enterprise* (Baltimore, MD: Johns Hopkins University Press, 2014) and Doogab Yi, *The Recombinant University. Genetic Engineering and the Emergence of Stanford Biotechnology* (Chicago and London: University of Chicago Press, 2015).

⁷On discoveries and innovations, see <http://www.nih.gov/about/almanac/historical/chronology_of_events.htm>; <<http://irp.nih.gov/our-research/accomplishments>>. Harriet R. Greenwald and Victoria A. Harden, eds, National Institute of Allergy and Infectious Diseases, *Intramural Contributions, 1887–1987* (Bethesda, MD: US Dept. of Health and Human Services, Public Health Service, National Institutes of Health, National Institute of Allergy and Infectious Diseases, 1987). On infrastructures that supported and shaped postwar biomedicine, including grants programmes, research contracts, (peer) review systems, the IRB and ethical review, consensus development conferences, and academic research centres see the following: On grants and peer review see note 51; Laura Stark, *Behind Closed Doors: IRBs and the Making of Ethical Research* (Chicago: University of Chicago Press, 2011); David H. Guston, 'Stabilizing the Boundary between US Politics and Science: The Role of the Office of Technology Transfer as a Boundary Organization', *Social Studies of Science*, 1999, 29, 87–111; Itzhak Jacoby, 'The Consensus Development Program of the National Institutes of Health', *American Journal of Psychiatry*, 1985, 142, 477–8; Gerald E. Markle and Daryl E. Chubin, 'Consensus Development in Biomedicine. The Liver Transplant Controversy', *Milbank*

Quarterly, 1987, 65, 1–24; Kenneth M. Ludmerer, *Time to Heal: American Medical Education from the Turn of the Century to the Era of Managed Care* (New York: Oxford University Press, 1999), *passim*. On efforts to cultivate public support for biomedicine, see for example, Judith Robinson, *Noble Conspirator: Florence S. Mahoney and the Rise of the National Institutes of Health*, (Washington, DC: Francis Press, 2001); Angela Creager, 'Mobilizing Biomedicine: Virus Research Between Lay Health Organizations and the U.S. Federal Government, 1935–1955', in Hannaway, ed., *Biomedicine in the Twentieth Century*, 171–201; Richard A. Rettig, *Cancer Crusade: The Story of the National Cancer Act of 1971* (Princeton, NJ: Princeton University Press, 1977). On NIH involvement in various health and social issues, see Rettig, *Cancer Crusade*; James T. Patterson, *The Dread Disease: Cancer and Modern American Culture* (Cambridge, MA: Harvard University Press, 1987); Gerald N. Grob, 'Creation of the National Institute of Mental Health', *Public Health Reports*, 1996, 111, 378–81; Gerald N. Grob, 'The National Institute of Mental Health and Mental Health Policy, 1949–1965', in Hannaway, ed., *Biomedicine in the Twentieth Century*, 59–94; Gerald N. Grob, *From Asylum to Community: Mental Health Policy in Modern America* (Princeton: Princeton University Press, 1991); Ruth Roy Harris, 'Brief History of the National Eye Institute', *Government Publications Review*, 1985, 12, 427–48; Ruth Roy Harris, *Dental Science in a New Age: A History of the National Institute of Dental Research* (Rockville, MD: Montrose Press, 1989); Lewis P. Rowland, *NINDS at 50: An Incomplete History Celebrating the Fiftieth Anniversary of the National Institute of Neurological Disorders and Stroke* (New York: Demos Medical Pub., 2003); Victoria A. Harden, *AIDS at 30: A History* (Washington, DC: Potomac Books, 2012); Grischa Metlay, 'Federalizing Medical Campaigns against Alcoholism and Drug Abuse', *The Milbank Quarterly*, 2013, 91, 123–62; Marian Moser Jones, 'Creating a Science of

“Elevator Speech” Excerpt

VISITOR: What’s so great about the IRP?

IRP SCIENTIST: Remember Marshall Nirenberg and the genetic code, Julius Axelrod and humoral transmitters? Fluoride for tooth decay; lithium for bipolar mental illness; blood tests to detect HIV and hepatitis; the first AIDS drugs; the first vaccines against hepatitis, Hemophilus influenza, and human papillomavirus? That’s the IRP. We’ve had 20-some Nobel Prize winners and 30-some Lasker winners.

VISITOR: But has the IRP done lately?

IRP SCIENTIST: Ketamine to reduce suicidal tendencies; immunotherapy to cure cancer; discovery of genes involved in stuttering and countless other disorders; world’s leader in MRI technology; Undiagnosed Diseases Program; world’s largest hospital dedicated to clinical studies...

Continue the ride at <http://irp.nih.gov/our-research/accomplishments>.

Figure 1: At a time when the future of the NIH’s intramural research program (IRP) is uncertain, intramural scientists are encouraged to have an elevator speech ready for visitors that highlights contributions the IRP has made to biomedical research. *The NIH Catalyst*, March-April 2014, 22 (2), 2.

Homelessness During the Reagan Era’, *The Milbank Quarterly*, 2015, 93, 139–178. For a sample of recent work on the NIH and human subjects research see Stark, *Behind Closed Doors*; Laura Stark and Nancy D. Campbell, ‘Stowaways in the History of Science: The Case of Simian Virus 40 and Clinical Research on Federal Prisoners at the US National Institutes of Health, 1960’, *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 2014, 48, Part B, 218–230. The enormous growth of the NIH budget after 1945 helped the introduction of expensive new

technologies and practices into biomedicine including the ultracentrifuge, the electron microscope, electrophoresis, computers, clinical trials and sequencing technologies. Lily E. Kay, *Who Wrote the Book of Life? A History of the Genetic Code* (Stanford, CA: Stanford University Press, 2000); Nicolas Rasmussen, *Picture Control: The Electron Microscope and the Transformation of Biology in America, 1900–1960* (Stanford, CA: Stanford University Press, 1997); Angela N. H. Creager, *The Life of a Virus: Tobacco Mosaic Virus as an Experimental Model, 1930–1965* (Chicago: University of Chicago Press, 2002); Peter

range of historical topics that a focus on the NIH may help to illuminate. However, among other themes, NIH records also provide insight into the complex relations between basic, clinical and (what has come to be called) translational research; the problematic place of preventive, nursing, behavioural, social science and heterodox approaches to research within biomedicine; and the changing relations between federal biomedical research, private industry, universities and medical schools since the 1940s.

It is thus no small wonder that historians of medicine and biomedicine have taken a growing interest in the organisation and its historical records. Most are aware that NIH records can be found in the National Archives at College Park; that the National Library of Medicine maintains a major collection of NIH papers; and that others can be found in the personal papers of former NIH researchers and administrators, and in the institutional records of the many organizations in receipt of NIH support. However, these do not account for all the records that exist, especially when one is dealing with the NIH's more recent history. There are other collections squirreled away in the NIH itself, in filing cabinets, on servers and computer systems, and within the records management system, many of which are uncatalogued and can be tricky to find. This article is primarily about these hidden collections: where they might be found, and how one might go about getting hold of them.⁸

Federal Records

In order to find such records, it is first useful to know what the NIH counts as a record. All records produced at the NIH are supposed to be dealt with according to the federal records schedule devised in collaboration with the National Archives and Records Administration (NARA), which sets out what should be preserved, what should be destroyed, and when.⁹ 'Federal records' are the property of the US Government: they do not belong to the individuals who produce them, and they come in a bewildering variety of forms.¹⁰ Put simply, a federal record is virtually any document in any medium produced by a scientist, physician or administrator in the course of his or her official duties for the federal government, be it in the field, the laboratory, the hospital ward or the office. Many of these individuals will be federal employees, but federal employees are not the only ones who produce

Keating and Alberto Cambrosio, *Biomedical Platforms: Realigning the Normal and the Pathological in Late-twentieth-century Medicine* (Cambridge, MA: MIT Press, 2003); Peter Keating and Alberto Cambrosio, *Cancer on Trial: Oncology as a New Style of Practice* (Chicago: University of Chicago Press, 2012); Joseph November, *Biomedical Computing: Digitizing Life in the United States* (Baltimore, MD: Johns Hopkins University Press, 2012); Hallam Stevens, *Life Out of Sequence: A Data-driven History of Bioinformatics* (Chicago: University of Chicago Press, 2013); Miguel García-Sancho, *Biology, Computing, and the History of Molecular Sequencing: from Proteins to DNA, 1945–2000* (New York: Palgrave Macmillan, 2012); Sejal Patel, 'Methods and Management: NIH Administrators, Federal Oversight, and the Framingham Heart Study', *Bulletin of the History of Medicine*, 2012, 86, 94–121; Sejal Patel, 'The Benevolent Tyranny of Biostatistics: Public Administration and the Promotion of

Biostatistics at the National Institutes of Health, 1946–1970', *Bulletin of the History of Medicine*, 2013, 87, 622–47.

⁸Some publications that make use of NIH records include useful essays on sources see November, *Biomedical Computing*, 323–30; Harry M. Marks, *The Progress of Experiment: Science and Therapeutic Reform in the United States, 1900–1990* (Cambridge: Cambridge University Press, 2000), 249–52.

⁹The NIH's record's schedule is available in *NIH Policy Manual 1743—Keeping & Destroying Records*: <<http://www1.od.nih.gov/oma/manualchapters/management/1743/>>.

¹⁰These forms include: letters, memoranda, reports, minutes, laboratory or field notebooks, instrument readings, photographs, sound recordings, movies, maps, books, drawings, databases, emails or in any other form or format—paper, microfilm, tapes, cards, disks and digital files.

such records. Others include federal contractors and sub-contractors, Commissioned Corps (Public Health Service officers), interns, guest researchers, visiting scientists, fellows and other non-government employees conducting business for or on behalf of the NIH through contractual relationships or memoranda of agreement.

Federal records do not necessarily include everything produced by the NIH. For example, many government employees and contractors use their official (nih.gov) email accounts for personal correspondence with family and friends, and to connect with professional and disciplinary colleagues. They also use government computer systems to order movie tickets, book restaurant tables and to shop online. Everyone using a government system for such purposes is warned that they have no right of privacy, but this does not mean that personal emails will be classed as federal records, nor does it mean that the private use of government computer systems will be categorised in this way. Federal records must relate to a government programme.¹¹ For historians the distinction between a federal and personal record may be moot, since personal and professional records may be as important as federal records to an historical account. But, it is an important distinction to be aware of because it determines how the NIH records management system treats these records. Personal records may not be preserved, and where they do end up accidentally preserved, they may later be destroyed or redacted. In addition, some records are particularly protected from public view, including patients' clinical records, reviewers' comments on grant applications and personally identifiable information such as social security numbers.

Although 'personal' or 'private' correspondence is not regarded as a federal record, this does not mean that all documents marked 'personal' or 'private' are excluded from the official record.¹² In some cases, personal or private correspondence may be mixed up with official correspondence in such a way as to make it part of the official record, or it may be that the NIH determines that the labels have been used inappropriately and that a document marked personal is in fact a government record. Official guidance is that where personal correspondence contains portions that require official action or response, those portions which require official action or response must be extracted and made a part of official files. However, this may not always be possible or practical. It should also be noted that research notes and reports created by NIH scientists in the course of their research for the NIH are official records that belong to the government, not the individual researcher. In some cases, diaries, appointment books and other schedules of personal activities are considered government records.¹³

The Life of a Record

If it is important to understand what counts as a record, it is also important to have some idea as to the life of a record. Records in fact have two lives: an ideal life as envisaged by the creators of the records schedule, and an actual life as dealt with practically by NIH scientists,

¹¹For documentary materials excluded by law (44 U.S.C. 3301) from the records of the Federal Government (called 'non-record') see: *NIH Policy Manual 1743—Keeping & Destroying Records*: <<http://oma1.od.nih.gov/manualchapters/management/1743/>>.

¹²The term private is tricky here, since users of government communication and computer systems have no

reasonable right of privacy regarding any communication or data that transits such systems. The government can monitor, intercept, record and search and seize any communication or data that goes through such systems.

¹³*NIH Policy Manual 1743* <<http://oma1.od.nih.gov/manualchapters/management/1743/>>.

physicians and administrators. The two are often not the same and in practice a hybrid system exists, combining elements of the ideal life with others forms of preservation and destruction. This hybrid system may ensure the preservation of 'personal' records, the destruction of federal records scheduled for preservation, or the preservation of records scheduled for destruction.

As regards the ideal life, a record (let us say a letter or email) would initially be stored in the files or on the computer or server of whoever produced or received the correspondence. At some point, when this document (and the files of which it was a part) was no longer in use, it would be taken by a records liaison—the official who oversees the management of the records of an Institute or Center (IC), sometimes also called a records manager or officer—and stored according to the records schedule mentioned above. The records schedule will determine the fate of this letter or email: it provides guidance as to whether the record should be classified as federal or personal, how long it should be stored by the NIH, and what should happen to it at the end of this time. Some records will be scheduled for destruction, others will gain a reprieve for later evaluation, and others will be transferred to the National Archives, where they will leave the control of the NIH and become the property of NARA.

Crudely put, the records schedule identifies federal records as either permanent or non-permanent: Permanent records are kept for 30 years, and then reviewed again by NARA archivists and added to Record Group (RG) 443: Records of the NIH.¹⁴ In the imagination of those who devised the records schedule, all records less than 30 years old would be held by the creating agency (in this case the NIH), and access would be either through a records liaison or via the Freedom of Information Act (FOIA) process. NIH records more than 30 years old and deemed historically significant would in this ideal vision of the records schedule be preserved and stored in the National Archives, specifically the Archives II facility in College Park, Maryland.¹⁵

This is the ideal. In practice, it often does not happen this way. Records can get lost or waylaid anywhere along the line. Space is at a premium in Bethesda, and often files are destroyed when an employee or contractor moves office or leaves the NIH, and the room is needed for someone else. Records are also routinely destroyed by administrators in the course of their daily work, as projects end and space is needed for new assignments: paper documents are shredded; electronic files deleted. It is possible that in some cases the records liaison does not do his or her job properly, and that records are destroyed as a consequence. Finally, those records that survive the weaning may get buried at the National Archives—the Archives is under-resourced and files can wait years for processing.

If records do not get lost or destroyed, they may be hoarded outside the records management system. Some administrators and researchers or their acolytes retain their records long after they should have been passed on to the records liaison; others will take them when they leave government service, unaware perhaps that they are the property of the US government; and others will conduct government business using private email accounts and servers. Thus government records can be found in private homes and servers across the country, and in university or medical school special collections. NIH administrators and researchers are supposed to be aware of the records schedule, and will likely have had

¹⁴*Ibid.*

¹⁵ <<http://www.nara.gov>>.

some training in it.¹⁶ But it is not a high priority for most, enforcement is poor, and there are repeated complaints about its complexity. (Who has the time to read the regulations, let alone follow them?) So papers languish in offices across the NIH, some destined for the dump, others preserved like holy relics, yet others spirited away to some distant location.

Records liaisons and government archivists lament such a state of affairs, and it is likely that records of historical importance are destroyed because it is impossible to enforce adherence to the records management schedule. But, the failings of the system have also resulted in the preservation of records that might have been destroyed had the records schedule been enforced. For example, referees' comments on grant applications are supposed to be destroyed once they are no longer needed for programmatic purposes. However, some have bypassed the shredder and delete button, and survive in collections outside of the records management system and NARA. It is likely that many other records scheduled for destruction are preserved outside the records management system, and never make it to the National Archives.

It should be clear, by now, that while the records schedule is supposed to preserve historically important records, what counts as historically important should not be conflated with what a historian needs to do his or her work. It is not uncommon for a historian working with NIH historical records to find evidence that documents relevant to their work were destroyed under the terms of the records schedule. This was the case in my first research project at the NIH: a study of a programme that at one time accounted for half the National Cancer Institute's (NCI) budget, and which involved the loan by the NCI of expensive and rare radium to hospitals across the United States. No other programme in the history of the Institute has come near to accounting for half its budget, yet it turned out that the records of this programme had been destroyed in the 1980s by administrators dutifully following the records schedule. I was only able to reconstruct its story because the NCI had preserved some documents in its LION database (see below) outside the records management system, and because it paid for me to visit the many hospitals and centres that had received government radium, local and state libraries that contained reports of the arrival of government radium in an area, and various state and local archives which held records of state and local involvement in the scheme. And these records revealed that the radium programme was more important than we had thought. The NCI, it turned out, was a New Deal project that loaned the radium not for research as was commonly thought, but for the routine treatment of poor patients with cancer.¹⁷

Where are the Records?

If you, the historian readers of this article, are getting the impression that the preservation of records can be a lottery—your impression is correct. The records that you want may have been destroyed, or they could be endangered: scheduled for destruction by a records liaison, or destined for the trash can (virtual or real) by an impending resignation, retirement

¹⁶This despite the fact that the US Department of Health & Human Services (HHS) currently requires all Federal employees, including those at NIH, to complete mandated Records Management training. See section 5.7 at <<http://www.hhs.gov/ocio/policy/2007-0004.001.html>>. The maximum penalty for the wilful and

unlawful destruction, damage or alienation of Federal records is a \$2,000 fine, three years in prison, or both. <<http://oma.od.nih.gov/public/MS/records/Pages/rtypes.aspx>>.

¹⁷Cantor, 'Radium and the Origins'.

or move, or by the insatiable demands for space in Bethesda. Equally, they may have been preserved against the odds: surviving the shredder of the records schedule, the resignations, retirements and moves, and the demands for space. It can at times be very difficult to figure out what has happened, even for those who work at the NIH.

So where to look? It is impossible for this article to identify all the places where a record may have ended up. There are simply too many collections of private or institutional archives that may hold NIH records to discuss here. My focus is on the major collections that may be buried within the organizational complexity that is the NIH, principally on its main campus in Bethesda and the surrounding region, including at NARA or the National Library of Medicine (NLM), and some online sources. This is not to say that the records you are looking for are in all or any of the places mentioned below—just that they could be there. The following may be regarded as a checklist; a catalogue of places to investigate.

1: A first place to look is the offices of the administrator, scientist or physician who undertook or oversaw the research. Current employees, fellows, guest researchers, special volunteers, tenants, and some contractors at the NIH can be found through the NIH's Enterprise Directory (NEDS).¹⁸ Former employees, fellows and others can be identified through historical telephone books most of which are held by the NIH History Office, and through the NIH Historical database, a listing of all NIH employees that is periodically updated. (See NIH History Office below.) Federal personnel records are kept at the Federal records centre in St Louis, and there are moves to make historical records of personnel open to the public.¹⁹ NIH contractors—large numbers of which work at NIH—are discussed below.

When approaching NIH scientists and administrators it is worth bearing in mind that some may be cautious about talking to outsiders. NIH employees are constantly reminded not to talk to journalists and other outsiders without getting official clearance—in part to ensure that upper echelons of the NIH hierarchy are not suddenly surprised by a report in the media, good or bad. The problem is that administrators and scientists can find it difficult to distinguish between an historical enquiry and a journalistic one, especially in the case of very recent history. Thus, you may find some employees unwilling to talk without official permission, and some that are suspicious of any outside interest in their work. Commercially or politically sensitive records such as technology transfer, intellectual property and animal experimentation can be a challenge.

This is not to say everyone at the NIH is suspicious of strangers, just that a historian should be aware of the culture of suspicion and caution about outsiders that circulates at the NIH. Indeed, it should be said that many scientists and administrators pay little heed to the rules about contacts with outsiders, and are happy to talk and provide whatever documents they have. But, it can take time and repeated visits to get to the records, to build trust and to get administrators and scientists to understand what your project is about and what you need from them. The Office of History can help with access to such people. The better known History of Medicine Division of the National Library of Medicine currently does not provide such help, except for access to its own collections.

2: The records liaison, officer or manager—usually a low-level bureaucrat, often over-worked, with other responsibilities besides records management, and sometimes concerned not to let information about NIH leak out to outsiders, since an inadvertent disclosure

¹⁸ <<https://ned.nih.gov/search/>>.

¹⁹ <<http://www.archives.gov/st-louis/federal-records/>>.

of sensitive information could come back to haunt him or her. Their main function is to manage and dispose of the vast amount of paper and electronic records produced by the NIH. They are not archivists—their job is to manage records not to preserve them, nor is it to provide access to outsiders. For this reason, it is usually best not to approach the records liaison directly, but to use an FOIA request (see below) or to go through someone else at the NIH. For example, if you have been able to identify a key administrator or scientist still at the NIH, he or she might be able to request records for you, as can the Office of History. Information on NIH records management policy and a list of records liaisons can be found on the NIH, Office of Management Assessment (OMA) website.²⁰

3: The Washington National Records Center (WNRC) in Suitland, Maryland, on the outskirts of Washington, DC.²¹ This is where the NIH stores records that are not in current use. Many of these records are simply awaiting their time for disposal according to the records schedule; some will go to NARA, most will be destroyed. Records at the WNRC belong to the NIH, and can be obtained by an FOIA request or by getting the permission of the ‘owner’ of the records—usually the NIH scientist or administrator responsible for the activities that produced the records, or his or her successors. The WNRC will not provide you with access to records without approval from the originating agency—in this case, that part of the NIH that sent them to Suitland.

Suitland is a records management facility, not a formal archive, and it does not maintain finding aids of the kind that you might find in a regular historical collection. Nevertheless, there are documents that can be used as a finding aid. Whenever records are sent to a Federal Records Center, such as Suitland, a particular form is generated, called a Standard Form (SF) 135.²² This form can be used as a proto-finding aid since it contains basic information about the records, including a brief description of the contents, the organisational component that created them, the number of boxes/files, inclusive dates, the person responsible for the records, any restrictions on access, and their (future) fate under the records schedule.²³ Records liaisons will have copies of the SF135s generated by his or her Institute or Center, and will likely use them to tell you whether records have been sent to the WNRC, what has happened to them there, and who is the responsible official at NIH. You can ask to see the SF135s if you do not wish to rely on the records liaison to identify which records are relevant to your project: they can be requested in much the same way as other records. Records liaisons often do not alert researchers to their existence.

As of 2013, the NIH began to use NARA’s data system—the Archives and Records Centers Information System (ARCIS)—to manage records transactions with Federal Records Centers such as the WNRC. ARCIS has the potential to be used as an electronic finding aid for all NIH records at Suitland, but as of the time of writing this potential has not been realised. Access to ARCIS is balkanised so that, with the exception of some senior records management officials, no one has complete access to all NIH electronic SF135s. Records liaisons will generally only have access to the SF135s for their IC. Thus, scholars researching the activities of more

²⁰ <<http://oma.od.nih.gov/public/MS/records/Pages/default.aspx>>. The list of records liaisons can be found at <<http://oma.od.nih.gov/public/Lists/AllDMSCContacts/Records%20Liaisons.aspx>>.

²¹ On Suitland Records Center see <<http://www.archives.gov/dc-metro/suitland/>>.

²² <<http://www.archives.gov/frc/forms/sf-135-intro.html>>.

²³ Federal Records Center, Preparing the Standard Form 135 (SF 135), Records Transmittal and Receipt <<http://www.archives.gov/frc/forms/sf-135-suitland-instructions.html>>.

than one Institute or Center will have little choice but to go through the records liaisons of all the ICs that they are interested in.

4: The National Archives at College Park, Maryland. At some point a fraction of the records held at the WNRC or at NIH will be transferred to the National Archives, and will usually be stored at the College Park site in records group 443.²⁴ These are known as permanent records—records that are determined by the Archivist of the United States to have sufficient historical or other value to warrant preservation. Permanent records are normally transferred to the National Archives when they are 30 years old, but they can be sent at any age when the NIH decides it no longer needs them, or that its needs can adequately be met by using NARA research rooms or by copies of the records. Any restrictions imposed by NIH on the use of records have to be acceptable to NARA and cannot violate FOIA. When records are transferred to NARA, they no longer belong to NIH, and NIH generally cannot recall them. They can be viewed at NARA's College Park site.²⁵

If you want to know which records NIH has sent to NARA, a key document is the SF258 (Agreement to Transfer Records to the National Archives), a form that is generated when records are transferred to NARA. Like the SF135, the SF258 can sometimes be a useful document for figuring out where records might be, especially if NARA has not got round to cataloguing them. Until recently, a paper SF258 form would also be used to initiate the transfer of electronic records. However, the SF258 is in the process of being replaced by transfer requests (TR) that can be created within NARA's new Electronic Records Archives (ERA) system. Records liaisons and some other NIH officials will have the SF258s and transfer requests. A further form to be aware of is the SF115 (Request for Records Disposition Authority) which is used by federal agencies to obtain disposition authority from NARA. It is generally used for unscheduled records, and can also be used to identify NIH records and their fate.²⁶

5: Some ICs maintain their own archives that are quite separate from the official records management system. They include:

- a National Cancer Institute (NCI): A rich archival collection is maintained by the NCI library in the Office of Communications and Education (OCE). This archival collection goes back to the 1950s, when an NCI administrator, Ora Marschino, began collecting historical materials to document NCI decision-making. Most of these materials can be located and requested using the search engine for the NCI's LION database.²⁷ Some of this material is only available in physical form, but a significant amount has been digitised and is available for immediate download. It is also possible to do full text searches across all the digitised documents in the repository, limited by date, subject and other criteria. But beware! Not all documents have been digitised and some documents are imperfectly scanned so that the text is not fully searchable. The LION database should be a required stop for

²⁴ <<http://www.archives.gov/research/guide-fed-records/groups/443.html>>.

²⁵ <<http://www.archives.gov/dc-metro/college-park/>>.

²⁶ Planning for the ERA began in 2001 with the intention of preserving the growing volume of government electronic records independent of their original hardware and software. The project has had a troubled history, and as of April 2015 (when this article went to press) there are rumours that it is to be quietly shelved. It is unclear what will replace ERA, nor is it known what

will happen to the new system of transfer requests, or to the vast amount of electronic material already in the system. For general information on the disposition of federal records see: <<http://www.archives.gov/records-mgmt/publications/disposition-of-federal-records/>>.

²⁷ <<https://lion.nci.nih.gov/>>. This link will not work outside of NIH; only via an NIH computer. For problems email nci-lion@mail.nih.gov.

anyone researching the history of NCI or a broader history of cancer. It also includes some records that may be of value to others researching the history of NIH more generally. It is easy and quick to search, so little time will be lost if it turns up nothing.

- b Office of the Director, NIH (OD/NIH).²⁸ The Office of the Director maintains a collection that includes correspondence and decision making materials from the Office of the Director, but also some outlier parts of the OD such as the Immediate Office of the Director (IMOD) and its component parts including the Office of Women's Health.²⁹ The collection comprises two forms of record: subject files (organised on an alpha-numeric taxonomy) and meeting folders, which include every meeting of every day. The meeting files comprise a mix of materials from airline tickets to briefing materials and are disposed of after seven years, with material in them which is deemed 'permanent' being transferred to the subject files. The records are being transferred to the NARA, and many have also been digitised and retained by the OD. The Office of the Director is the central office at NIH that sets policy and plans, manages and coordinates the programmes and activities of the various components of NIH. Anything that is likely to have come to the attention of the director of the NIH will likely have come through this office.³⁰
 - c National Human Genome Research Institute (NHGRI). In 2012, the NHGRI launched an institute-wide initiative under the historian Christopher Donahue to collect and preserve information on its role in The Human Genome Project and other genomics programs. The project includes a searchable archival database which contains digital NHGRI files (including both digitized paper files and born-digital documents) and oral histories undertaken as part of the project. The NHGRI website suggests that public access will be restricted to selected documents within the database.³¹
- 6: The Office of History at the National Institutes of Health: not to be confused with the History of Medicine Division (HMD) of the National Library of Medicine below (see also Online Sources at paragraph 10). The Office maintains a variety of collections including:
- a The papers of some NIH scientists, ICs and programmes. (This is a small collection, and current History Office policy is in flux, but generally papers are stored for a limited time until they can be found a more permanent home such as NARA or the NLM. The History Office archivist will be able to provide you with details of current holdings.)³²
 - b Subject files/study collections (A miscellaneous collection of files on a variety of subjects, generally used by the Office to answer enquiries or as part its research or exhibits programmes. Again contact the archivist.)

²⁸OD in NIH-speak refers to the Office of the Director, but there are many ODs: each Institute and Center has an OD, as do many Divisions within these ICs. Thus a policy issue that affected, for example, the Division of Cancer Prevention (DCP) of the NCI may have been discussed in the OD/DCP, the OD/NCI and the OD/NIH among other places, and records may have survived in archives or records groups associated with all of these ODs. OD/NIH refers to the Office of the Director of the NIH.

²⁹Office of Planning & Communication, Office of Laboratory Animal Welfare, Office of Policy for Extramural Research Administration, Office of Extramural

Programs, Office of Research Information Systems, Office of Administrative Operations.

³⁰The NIH/OD collection was created by Richard Mandel, who is the best NIH contact for current information.

³¹<<http://www.genome.gov/27557501>>. On the Human Genome Project and the role of NIH in it see also Robert M. Cook-Deegan, *The Gene Wars: Science, Politics, and the Human Genome* (New York: W.W. Norton, 1994); Daniel J. Kevles and Leroy E. Hood, *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (Cambridge, MA: Harvard University Press, 1992).

³²<<http://history.nih.gov/archives/>>.

- c National Institutes of Health data books. (These yearly publications provide information on budgets, grants, organisation and other aspects of NIH. Some of this data is now available online).³³
 - d Photo and Image collection. (Many, but not all, of these are available via the web (see Online Sources at paragraph 10), contact the archivist for more information and access).
 - e The NIH Historical database. (A listing of all NIH employees that is periodically updated. Note that this will not give you the details of the large number of contractors. For example should anyone be interested in the work of David Cantor—one-time deputy director of NIH History Office, and formerly at NCI and NLM—the database notes his employment from 2000 to 2001 in the Office of the Director, but not his long period as an NIH contactor and subcontractor from 2001 to 2008.)
 - f NIH telephone books (Useful for identifying the names of NIH personnel since 1950. These publications are divided into an alphabetical listing and an organisational listing. It is possible to identify, for example, which laboratory or office an intramural investigator or NIH administrator worked in and his or her laboratory or office chief.)
 - g The NIH Scientific Directory and Annual Bibliography for 1956–1992. (Held by the NIH History Office and the NIH Library.)
 - h The DeWitt Stetten, Jr., Museum of Medical Research. (This component of the History Office is an important repository for historic biomedical research instruments and other NIH artefacts, predominantly those used at the main campus at NIH. An online finding aid is available, and historians should also contact the curator.)³⁴
- 7: The National Library of Medicine (see also Online Sources at paragraph 10). The NLM maintains some of the richest, easily accessible, collections on the history of NIH. This is a good place to base one's self while waiting for any records that might be in the records management system to emerge. The Archives and Modern Manuscripts Collection administered by the NLM's History of Medicine Division (HMD) includes the papers of NIH directors, intramural scientists and administrators, and NIH organisations and other records.³⁵ The NLM collection is constantly growing and there is an online finding aid.³⁶ The official archive of

³³ <<http://report.nih.gov/nihdatabook/>>.

³⁴ <<http://history.nih.gov/museum/>>.

³⁵ As of January 2014 the directors' collection included the papers of Donald S. Fredrickson, Robert Q. Marston, W. H. Sebrell, Harold Varmus, Bernadine Healy, Rolla E. Dyer and James A. Shannon (although mainly his papers before and after his time at NIH). As of January 2014 the scientists' and administrators' collection included papers of Harold Leroy Stewart (cancer research), Bertram Brown (NIMH), Louis Sokoloff (neurochemist), John T. Watson (NHLBI), Julius Axelrod, John B. Calhoun, Martin Rodbell, D. Carleton Gajdusek, Christian Anfinsen, Marshall W. Nirenberg, Sara E. Branham (bacteriologist), Margaret Pittman, Clarence Dennis, Murray J. Shear, Howard Bartner (medical illustrator), DeWitt Stetten, Jr. (biochemist), Paul D. MacLean (brain and behavioral research), Paul D. MacLean (chemist/biochemist), John Daly (chemist), Grant L. Rasmussen (neuroanatomist), Telford H. Work, Bernhard Witkop, Alexis I. Shelokov (virologist/physician), Abraham Goldin (tumor

biology/cancer chemotherapy), Thomas C. Chalmers (clinical trials), H. Trendley Dean (dental research), Ruth L. Kirschstein. As of January 2014 the NIH organisations and other records collection included papers of the NIH Clinical Center Office of Medical Services, 1953–1987 (Medical Board); the NIH, Office of the Director, Congressional Inquiries Correspondence; NIH Office of the Associate Director, Program Planning and Evaluation Records; NIH Office of Extramural Research animal research records; Animal Research at the NIH. Video Cassette of Television Programs on the Topic, 1982–1993; the NIH Centennial Celebration Collection; notes, biographical files and correspondence of Dr Wyndham D. Miles for his (unpublished and uncompleted) history of the NIH among others, and the papers of Mike Gorman who lobbied with Mary Lasker and others on many health issues including NIH research.

³⁶ <<http://oculus.nlm.nih.gov/cgi/ff/findaid/findaid-idx?page=home;c=nlmfindaid;cc=nlmfindaid>>.

the NIH is NARA not the NLM, but NARA seems content at the moment not to question NLM's collection of NIH materials. Note also that the NLM does not collect museum artefacts, and that where the NLM does acquire a collection that includes such objects, the artefacts are generally separated out and may be sent to museum collections elsewhere such as the Stetten Museum (paragraph 6(h)).³⁷

8: The NIH Library: (see also Online Sources at paragraph 10).³⁸ This is a research library that serves the various programmes of the NIH. It should not be confused with the much larger NLM. The NIH Library has a small collection of historical materials, including some annual reports of various ICs and some other rare documents. Scans of many of these are now available at the Internet archive (Online Sources, paragraph 10), but it is still worth checking for archival materials and rare publications. The library is currently located in Building 10, the Clinical Center on the Bethesda campus. Some satellite sites are located in the Bethesda areas and at other NIH locations across the country.

9: Local contractors. There are numerous private companies that service the NIH. It is likely that most will be cautious about opening their records to outsiders, but it doesn't hurt to try, especially if you are able to get someone in the contracting agency (the NIH) to vouch for you. The range of services they provide is enormous. Some provide temporary staff (Kelly Services currently has an office at the NIH for this purpose), others organize meetings, provide medical and scientific equipment, data processing services, cleaning services, food, security and much more, whatever the NIH needs.

Identifying contractors is not always easy. Current contractors will be in the System for Award Management (SAM) e-procurement system.³⁹ The government and some private organisations provide historical information on contracts and contractors, but these generally address relatively recent contracts, and some databases are unwieldy to use.⁴⁰ You may also identify contractors through the programme files held by the NIH, or through publications like *The Cancer Letter* (see paragraph 10) that report on them. Also beware that the NIH, like many government agencies, 'buries' people and projects in contracts. So, for example, if the NIH wants to recruit someone to work on a project and anticipates problems in hiring that person, he or she may be attached to an existing contract and hidden within it: this contract may have no connection to the project for which the person was recruited. Equally, contractors may seek to 'cleanse' an NIH employee, by supporting him or her for a while on non-NIH projects or with non-NIH funds, so as to take advantage of his or her former involvement with NIH.

10: Online Sources:

a The Internet Archive:⁴¹ A variety of organisations have mounted NIH materials on the Internet Archive including annual reports, films, internal reports and other rare materials. This is always worth checking as the number and variety of records grows almost daily. In addition, the NIH's numerous websites have been crawled periodically since 1996, snapshots of which have been mounted on the Internet Archive's Wayback

³⁷Hank Grasso and Michele Lyons, 'A Life Collected. Joseph Edward Rall (1920–2008)', *The NIH Catalyst*, March–April 2014, 22, 1, 10–12.

³⁸The website of the NIH library is: <<http://nihlibrary.nih.gov>>.

³⁹<<https://www.sam.gov>>.

⁴⁰Government contracts back to the year 2000 are available in <<http://www.usaspending.gov>>. See also <<https://www.fbo.gov>>. For private databases see e.g. <<http://www.fedspending.org/>>; <<http://www.contractormisconduct.org/>>.

⁴¹<<https://archive.org>>.

- Machine.⁴² The crawls have captured a spectacular collection of rare and sometimes otherwise difficult to find digital documents: not only the websites themselves (which include information on organisational structure, personnel and mission statements and revisions of mission statements), but also much of the material that the NIH mounts on its websites—health advice literature, education leaflets, newsletters, films/videos, countless official reports, policy statements, photos and more. The snapshots of the websites and their accompanying materials are organised by the date at which they were captured.
- b NIH Photo Galleries and Videocasts. The NIH maintains a number of photo galleries, mainly intended for journalists and focused on current activities and people. However, some older materials are also available through these sites.⁴³ Videocasts of NIH seminars, conferences, meetings and other events back to 1993 are available as on-demand video or a downloadable podcast.⁴⁴
 - c NIH Library. The NIH Library has made available numerous reports via the Medical Heritage Library and the Internet Archive.⁴⁵
 - d NIH newsletters and blogs. There are countless such publications, but two of the most useful are the *NIH Record* (an internal newsletter digitised back to 1949), and *The NIH Catalyst* (the newsletter of the Intramural Research Program, which is archived online back to 1996).⁴⁶ Other newsletters and blogs may be viewed on the various NIH websites or through the Internet Archive (paragraph 10(a)).
 - e NLM: The NLM maintains a variety of useful online sources that include NIH material including: *Images for the History of Medicine*, *Profiles in Science*, *Digital Collections* (an online archive of biomedical books and videos).⁴⁷
 - f NIH History Office: The History Office online collections include a finding aid for its archival and museum collections; bibliographical and other reference collections and an oral history collection.⁴⁸
 - g There are a variety of non-NIH magazines and newsletters that routinely comment on issues to do with NIH. One of the best is *The Cancer Letter* (Originally *Cancer Newsletter*) set up in the early 1970s to report on cancer research funding, legislation, policy issues, drug development, often with a focus on NCI. Its reports are often better than the NCI's own archives, and it seems to have been used by (often anonymous) dissenters at NCI to raise issues about the Institute's policies.⁴⁹ Numerous other websites, blogs, magazines and newsletters comment on other aspects of NIH, as do online science and medical journals such as *Nature*, *Science*, *The New England Journal of Medicine*, *Journal of the American Medical Association*, *The Lancet* among others. Newspapers such as the *New York Times* and the *Washington Post* regularly report on NIH.

⁴²<<http://archive.org/web/> (Type 'www.nih.gov' into the search engine).

⁴³<<http://www.nih.gov/about/nihphotos.htm>>.

⁴⁴<<https://videocast.nih.gov/>>.

⁴⁵<<http://www.medicalheritage.org/2012/09/the-medical-heritage-library-adds-national-institutes-of-health-annual-reports-from-the-nih-library/>>; <<https://archive.org/details/nihlibrary>>.

⁴⁶For the *NIH Record*, see <<http://nihrecord.od.nih.gov>>; for *The NIH Catalyst*, see <<http://irp.nih.gov/catalyst>>.

⁴⁷For the *Images for the History of Medicine*, see <<http://ihm.nlm.nih.gov/luna/servlet/view/all>>; for *Profiles in Science*, see <<http://profiles.nlm.nih.gov>>; for the *Digital Collections*, see <<http://collections.nlm.nih.gov/>>.

⁴⁸For the archival and museum collections, see <<http://nih.pastperfect-online.com/37870cgi/mweb.exe?request=ks>>; for bibliographical and other reference collections, see <<http://history.nih.gov/research/sources.html>>; for the oral history collection, see <http://history.nih.gov/archives/oral_histories.html>.

⁴⁹<<http://www.cancerletter.com>>.

Research, Contracts and Grants

Finding records on research supported by the NIH will depend in part on whether it is classified as intramural (research undertaken at the NIH campus in Bethesda and a few other locations) or extramural (research supported by grants). Until the 1940s the distinction was largely meaningless: virtually all research was undertaken by employees and based at the NIH or its predecessor organizations.⁵⁰ This began to change in the late 1930s when the NCI started to award grants to outside individuals and organisations, and the NIH followed suit in the 1940s.⁵¹ The grants system was the beginning of the distinction between intramural and extramural research, and funding for the latter rapidly began to dwarf funding for research undertaken by scientists at NIH.⁵² At times, intramural scientists have pushed back, for example in the 1960s and 1970s when administrators tried to use contracting mechanisms to expand intramural research.⁵³ But this met resistance from universities, medical schools and their allies in Congress, and today the intramural programme accounts for only 10 per cent of the NIH's research budget, and there are restrictions on the use of contracting mechanisms for funding research.

Research undertaken as part of the intramural programme will be dealt with according to the records schedule. The notebooks, correspondence, diaries, databases and other records produced by NIH scientists in the course of their official duties (including their research) are classified as federal records, and should be obtainable through an FOIA request or via other informal means, unless they include confidential information such as individual patient records or commercially sensitive information. In practice intramural researchers may regard their notes as their own, but it is worth remembering that they are not. Information on intramural research supported under contract may be preserved in programme files, such as those of the Special Virus Cancer Program of the NCI.⁵⁴ But as mentioned above,

⁵⁰Harden, *Inventing the NIH*; Kraut, *Goldberger's War*.

⁵¹Philip Sapiro and Jeanne Brand, 'The National Institutes of Health Research Grant Program and the History and Sociocultural Aspects of Medicine', *Bulletin of the History of Medicine*, 1959, 33, 67–74; Daniel M. Fox, 'The Politics of the NIH Extramural Program, 1937–1950', *Journal of the History of Medicine and Allied Sciences*, 1987, 42, 447–66; William H. Schneider, 'The Origin of the Medical Research Grant in the United States: The Rockefeller Foundation and the NIH Extramural Funding Program', *Journal of the History of Medicine and Allied Sciences*, advance publication, first published online 26 February 2014, doi:10.1093/jhmas/jrt074; Stephen P. Strickland, *The Story of the NIH Grants Program* (Lanham, MD: University Press of America, 1989); Richard A. Mandel, *A Half Century of Peer Review, 1946–1996* (Bethesda, MD: National Institutes of Health, Division of Research Grants, 1996); Daryl E. Chubin and Edward J. Hackett, *Peerless Science: Peer Review and U.S. Science Policy* (Albany, NY: State University of New York Press, 1990).

⁵²Buhm Soon Park, 'The Development of the Intramural Research Program at the National Institutes of Health After World War II', *Perspectives in Biology and Medicine*, 2003, 46, 383–402; Buhm Soon Park, 'Disease

Categories and Scientific Disciplines: Reorganizing the NIH Intramural Program, 1945–1960', in Hannaway, ed., *Biomedicine in the Twentieth Century*, 27–58.

⁵³Stephen P. Strickland, *Politics, Science, and Dread Disease: A Short History of United States Medical Research Policy* (Cambridge, MA: Harvard University Press, 1972); David Cantor, 'Between Prevention and Therapy: Gio Batta Gori and the National Cancer Institute's Diet, Nutrition and Cancer Programme, 1974–1978', *Medical History*, 2012, 56, 531–61. Doogab Yi's research on the history of the Special Cancer Virus program and Robin Wolfe Scheffler's unpublished PhD dissertation, 'Cancer Viruses and the Construction of Biomedicine in the United States from 1900 to 1980' (Yale University, 2014), both explore the politics and practices around NIH contract mechanisms. See also Robin Wolfe Scheffler, 'Managing the Future: The Special Virus Leukemia Program and the Acceleration of Biomedical Research', *Studies in History and Philosophy of Science Part C: Studies in History and Philosophy of Biological and Biomedical Sciences*, 2014, 48, Part B, 231–249.

⁵⁴On the cancer virus programme and contractors see the work of Doogab Yi and Robin Wolfe Scheffler, note 65.

contractors may be unwilling to open their files to you. Some of their records may be classified as federal records (and hence vulnerable to an FOIA request), though probably not everything that may interest you as a historian.

Research undertaken as part of the extramural programme can be more of a problem. Although the extramural programme produces a lot of records concerned with the running and evaluation of the programme (some of which may be available in the various locations mentioned above), other historical records can be difficult to obtain. Abstracts of grants awarded before 1995 are printed in the annual bibliography of NIH grants.⁵⁵ Abstracts of grants awarded since 1992 are available online via from the Research Portfolio Online Reporting Tools.⁵⁶ Copies of full grant applications, when available, can be requested through the FOIA process. Grants that were not funded are more of a problem. Under the Privacy Act of 1974, the Federal government is not allowed to keep records of grants that were not funded.⁵⁷ All such records are supposed to be destroyed, although given the vagaries of the records management system this does not always happen.

Apart from basic information such as the approval date and grant amount it can be a challenge to find more on the history of a particular grant's approval process. For most grants there is no permanent record of the peer review and approval process, such as the 'pink sheet' comments of the initial review group or 'study section'. The National Archives does not routinely keep case files for grants. In a few cases, an individual scientist may have

⁵⁵Records of NIH grants to 1995 can be found in the following publications: David E. Price, *Research Grants Awarded by the Public Health Service, Public Health Reports Supplement 205*, (Revised 1948; Addendum 1949); *PHS Research Grants in Aid* (30 June 1948): <http://history.nih.gov/research/downloads/PHS_ResearchGrantsinAID-June30th1948.pdf>; Ernest M. Allen, *Research Grants and Fellowships Awarded by the National Institutes of Health of the Public Health Service, September 2, 1949 Through August 31, 1950* (Washington, DC: Public Health Service Publication No. 63, 1951); Ernest M. Allen, *Research Grants and Fellowships Awarded by the National Institutes of Health of the Public Health Service, from Fiscal Year 1951 Funds* (Washington, DC: Public Health Service Publication No. 164, 1952); *Public Health Service Research Grants and Fellowships Awarded from Fiscal Year 1952 Funds* (Washington, DC: Public Health Service Publication No. 289, 1953); *Research Grants and Fellowships Awarded by the Public Health Service, Fiscal Year 1953 Funds* (Washington, DC: Public Health Service Publication No. 339, 1954); *Research Grants and Fellowships Awarded by the Public Health Service, Fiscal Year 1954 Funds* (Washington, DC: Public Health Service Publication No. 423, 1955); *Research Grants and Fellowships Awarded by the Public Health Service, Fiscal Year 1955 Funds* (Washington, DC: Public Health Service Publication No. 469, 1956); *Research Grants and Fellowships Awarded by the Public Health Service, Fiscal Year 1956 Funds* (Washington, DC: Public Health Service Publication No. 532, 1957); *Research Grants and Awards, National Institutes of Health, Fiscal Year*

1957 Funds (Washington, DC: Public Health Service Publication No. 571, 1958); *Public Health Service Grants and Fellowships Awarded by the National Institutes of Health, Fiscal Year 1958 Funds* (Washington, DC: Public Health Service Publication No. 624, 1959); *Public Health Service Grants and Awards by the National Institutes of Health, Fiscal Year 1959, Part I: Health Facilities Construction and Research Projects* (Washington, DC: Public Health Service Publication No. 701, Part I, 1960); *Public Health Service Grants and Awards by the National Institutes of Health, Fiscal Year 1960, Part I: Health Facilities Construction and Research Projects* (Washington, DC: Public Health Service Publication No. 777, Part I, 1961); *Public Health Service Grants and Awards by the National Institutes of Health, Fiscal Year 1961, Part I: Health Facilities Construction and Research Projects* (Washington, DC: Public Health Service Publication No. 883, Part I, 1962); *Research Grants Index* (Bethesda, MD: US Dept. of Health, Education, and Welfare, Public Health Service, National Institutes of Health, Division of Research Grants; Washington, (annually) 1961–1975); *Research Awards Index* (Bethesda, MD: US Dept. of Health, Education, and Welfare, Public Health Service, National Institutes of Health, Division of Research Grants; Washington, (annually) 1976–1987); *Biomedical Index to PHS-Supported Research* (Bethesda, MD: US Dept. of Health and Human Services, Public Health Service, National Institutes of Health, Division of Research Grants, (annually) 1988–1995).

⁵⁶<<http://projectreporter.nih.gov/reporter.cfm>>.

⁵⁷<<http://oma.od.nih.gov/ms/privacy/>>.

donated grant records to a private archive such as a university's special collection, and sometimes an IC keeps grant information beyond the scheduled destruction date. Official guidance is that most NIH official grants case files are not regarded as historically valuable, but that grant case files that document events of historical importance should be brought to the attention of the NIH Records Officer so that an evaluation can be undertaken as to whether they should be transferred to the National Archives. Such 'events' cover a broad range of subjects, including the cure of a disease, a major scientific discovery, a major health programme or other event, which generates significant media, public or historic interest.⁵⁸ Records held by individuals and organisations in receipt of NIH grants will generally not be in the Bethesda area, and are not dealt with here.

Freedom of Information

It is likely that at some point someone at the NIH will advise you to submit a Freedom of Information Act (FOIA) request. It is, however, worth being cautious about following this advice. Often records are available without an FOIA request, and if other routes do not work out, it is always possible to submit an FOIA request later on. Initiating one at an early stage can sometimes be counterproductive.

In the first place, administrators sometimes see submitting an FOIA request as a hostile move. This may come as a nasty surprise, since FOIA requests may be initiated on the advice of an NIH employee, such as a records liaison. So the unwary may take the advice, and then find themselves stymied by an organisational bureaucracy that suddenly and mysteriously closes down, making it difficult to get access to sensitive materials or to get interviews. Part of the reason for this conflict of response concerns the public image of the NIH: as mentioned before, employees and contractors are constantly warned not to talk to journalists without clearing it with the communications office, or to make material available to them without permission. For officials, it is often impossible to distinguish between contemporary history and what the NIH might regard as muckraking journalism. For this reason, it is best to try other approaches before attempting to get records via FOIA.

In the second place, even if an FOIA request is not seen as a hostile move, it may set in motion bureaucratic mechanisms that are very unwieldy and cumbersome methods for getting information.⁵⁹ The law sets specific deadlines for replying to FOIA requests: currently 20 working days from receipt of the initial request, and agencies are supposed to receive a time extension only in unusual or exceptional circumstances. However, agencies have exceeded the 20 working-day deadline, sometimes by months or even years, not least

⁵⁸ <<http://oma1.od.nih.gov/manualchapters/management/1743/>>, 4000-B-1

⁵⁹ One source of delay can be a result of tolling. In accordance with the amendments to the FOIA in the OPEN Government Act of 2007, the NIH may toll (i.e. stop the clock on FOIA processing) your request by asking you for additional information that will assist NIH in processing your request and as 'necessary' to clarify fee-related issues. There is no statutory limit on the number of times an agency may toll for the purpose of clarifying fee matters. In either circumstance, the NIH receipt of the requester's response ends the

tolling period and the response time clock resumes. For advice on submitting an FOIA request, and issues regarding delay and denial see Public Citizen's, 'How to File a FOIA Request: A Guide', <<http://www.citizen.org/Page.aspx?pid=458>>, or the National Security Archives, <<http://www2.gwu.edu/~nsarchiv/nsa/foia.html>>. See also Kristin Adair and Catherine Nielsen (and by Meredith Fuchs, Yvette M. Chin, Malcolm Byrne and Tom Blanton, eds., *Effective FOIA Requesting for Everyone. A National Security Archive Guide* (Washington, DC: The National Security Archive, 2008).

because agency FOIA offices suffer from a backlog of requests. You can help the NIH FOIA office process your request by keeping it as brief and targeted as possible, and by undertaking as much research as you can on where the documents requested could be located within the agency: documents such as the SF158 and SF115 may provide basic information like the agency's box number, file or document number. If approved (and approval is not a certainty) this does not mean that you will be given direct access to the material. Some low-level bureaucrat will get the material for you and send you photocopies or scans. For small requests there will be no charge, but beyond that you may have to pay. So you really need to know exactly what you are looking for if you decide to submit an FOIA request. You can review the NIH FOIA website for general information about the process.⁶⁰

Both of these aspects are reasons for caution, but they do not mean that you should avoid FOIA. FOIA officers can be helpful, and not all agree with the culture of suspicion of outsiders, and some think it healthy for the public to know how their dollars are being spent, at least within the FOIA framework. Nor is it necessarily slow to obtain records. When—as Deputy and Acting Director of the Office of History—I received an FOIA request for documents that might be held by the Office, the turnaround time was generally very quick, often only a few days. But it is worth being aware of the potential problems, and to look for alternatives, and to get as much information as possible before filing an FOIA request, including from NIH scientists, physicians and administrators. It may be that at some stage an official will block access without an FOIA request, but the research up to this point can be used to help an FOIA officer locate the records you need. In one case a historian who approached the History Office found his/her informal requests for documents blocked by an administrator. However, earlier correspondence between the History Office, the historian, various NIH officials (including the administrator who blocked access) mentioned the existence of various caches of records, and the researcher was able to use this correspondence to identify which records he/she wanted in his/her FOIA request. The correspondence that led to the blocked request for records allowed the researcher to specify which records he/she wanted in the FOIA request.

It is also important to know that not everything is available through an FOIA request. In general personal information is excluded, as is patentable or other commercially valuable information.⁶¹ In addition in the case of grants, NIH routinely redacts the score a grant application received (its priority score), the direct costs recommended and the evaluation and opinion of the experts who reviewed the grant application, on the grounds that it ensures that experts are open and honest in their opinions.

Insiders and Outsiders

All this should make it clear that getting access to NIH records may involve much more than filling out the document request slip used in more formal historical archives. It can take time, repeated visits and innumerable explanations and justifications of your project, as you try to figure out whether any records survive, where they might be, and who you need to talk to to

⁶⁰<<http://www.nih.gov/icd/od/foia/>. See also <http://www.foia.gov/>>.

⁶¹Personal information includes social security numbers; birthdates; information that reflects an individual's personal income (percentage of effort, institutional

base salary); information regarding pending or non-final support; the source of any support received from non-public sources; references to unpublished material; <<http://www.nih.gov/icd/od/foia/grants.htm>>.

get access to them. You may find that the filing cabinets fly open, but equally you might find that the records remain locked behind steel doors, if indeed you are able to identify their locations, or whether or not they exist. As an outsider to the NIH you may be treated as someone with something to offer the NIH or groups and individuals within it—senior administrators occasionally turn to history to understand why the NIH works in the strange ways it does, and others hope that historians may be a route to public recognition. But equally you may be treated as suspect, an outsider with questionable motives, an intruder with no good reason to be there. Either way it can be a long wait, and it is worth having other things to do in the DC area during the downtime—perhaps the NLM, the Smithsonian, the Library of Congress, or the FDA.⁶²

It can be easier for historians employed by the NIH to get access to its organisational records. Indeed, the experience of the Office of History is that staff and post-doctoral fellows generally had good access to records, and the time to find them.⁶³ In a few cases, projects were stillborn because the NIH felt that they were too politically sensitive, and some staff and fellows felt pressure to toe a party line, much as with other sponsored histories. (It is a paradox that while the NIH is intensely concerned with conflicts of interest, it does not seem to regard as a conflict of interest the fact that staff and fellows were employed by the organisation about which they were writing.)⁶⁴ The Office's fellowship programme is currently suspended due to financial problems, and it is likely to be some time before it is resurrected. In the past the NCI's Cancer Prevention fellowship programme supported historical and anthropological research related to cancer.⁶⁵ Things may change in the future, but such appointments are very rare now, and the NIH is generally not willing to finance historical research in its other intramural fellowship and training programmes.⁶⁶ It should be noted that as an extramural programme, the NLM's Grants for Scholarly Works in Biomedicine and Health (sometimes informally known as its publication grant programme) does not do this. Awardees are not employees or fellows of the NIH.⁶⁷

One avenue to temporary 'insider' status is a non-stipendiary special volunteer or guest researcher appointment—the difference is that volunteers do research for the NIH; guests do their own research using the resources of NIH. These cost the NIH very little, except

⁶²For the Smithsonian, see <<http://siarchives.si.edu/sia/main.html>>; <<http://www.siris.si.edu/>>; for the Library of Congress, see <<http://www.loc.gov/>>. In 1972 the NIH Division of Biologics Standards (formerly the Bureau of Biologics) was transferred administratively from the NIH to the Food and Drug Administration (FDA). Today it is known as the Center for Biologics Evaluation and Research (CBER). Its buildings remain on the NIH campus in Bethesda. For information about biologics activities since 1972, contact the FDA Historians: Suzanne J Junod (<sjunod@ora.fda.gov>) and John Swann (<jswann@ora.fda.gov>) phone (301) 443-6367. For information on biologics activities before 1972, or for other questions on biologics activities before 1972, contact the Office of History at the NIH. More generally on biologics see Alexander von Schwerin, Heiko Stoff and Bettina Wahrig, eds, *Biologics: A History of Agents Made from Living Organisms*

in the Twentieth Century (London: Pickering & Chatto, 2013).

⁶³Most fellows were appointed as Intramural Research Training Award (IRTA) fellows. For IRTA and other intramural training programmes see <<https://www.training.nih.gov>>.

⁶⁴On sponsored histories see David Cantor, 'The Politics of Commissioned Histories (Revisited)', in Ronald E. Doel and Thomas Söderqvist, eds, *The Historiography of Contemporary Science, Technology, and Medicine: Writing Recent Science* (London and New York: Routledge, 2006), 45–66.

⁶⁵<<http://cftp.nci.nih.gov>>. Historian fellows included Mark Parascandola who worked on the history of smoking. Anthropologists included Christine Holmberg and Simon J. Craddock Lee.

⁶⁶For details of these programs see <<https://www.training.nih.gov>>.

⁶⁷<<https://www.nlm.nih.gov/ep/GrantPubs.html>>.

time and some minor bureaucratic hassle, and a friendly senior administrator or scientist may be able to arrange it, as may the History Office and the NLM's History of Medicine Division. Ask! But beware there will be a lot of paperwork, a security check and foreign nationals will be required to demonstrate that they have appropriate immigration status—legal residency or an appropriate visa. Such appointments can help, but they do not guarantee access to records. Astute administrators will easily identify someone as a visitor or guest, and some may not regard a guest or visitor as truly part of NIH, and so block access to records without a FOIA request.

Conclusion

The records buried away in the NIH can be very rich, but they can also be very difficult to locate and view. The foregoing has suggested ways of doing this, where one might look, how the NIH may treat the records it produces, and those historians who wish to view them. In the past the History Office would have provided help in navigating this labyrinth of uncertainty and organisational complexity. However, its ability to continue to do so in the future is compromised, which will impoverish future historical research on the NIH and biomedicine, and undermine the ability of policy makers, administrators and biomedical researchers (within and without the NIH) to understand the organisation and its activities.

All this makes a case against the downsizing of the History Office. Not only has the Office helped historians and other scholars find their way through the complexities of the records management system; vouched for them to officials suspicious of their motives; guided them through the FOIA process; provided access to internal NIH computer systems and databases; supported post-doctoral fellows; and created guest and volunteer positions for outside historians: it has also ensured the preservation of historically valuable records that might otherwise have been lost. Indeed, its tradition of acting as an advocate for and guide to outside historians has meant that the latter have helped in the task of preserving the NIH's historical record. Even in times when funding was better, it was impossible for the small staff of the History Office to identify everything in need of preservation, and its extended network of visiting historians and post-doctoral fellows offered valuable additional opportunities to identify important collections, sometimes in danger of destruction. With its post-doctoral fellowship programmes currently suspended, and its diminished contacts with professional historians and other scholars, such preservation efforts are compromised. The erosion of such capacity is a loss to historians, biomedicine, the NIH, policy makers, archivists and the public which supports this organisation through its tax dollars.

Acknowledgements

This paper has benefited from the knowledge of the staff of the Office of History at the National Institutes of Health: Barbara Harkins, Hank Grasso, Michele Lyons, and especially Victoria Harden and the post-doctoral fellows all helped me learn my way round the records system at the NIH, and corrected my many mistakes and misconceptions. Of course, all errors and opinions in this article are my own.