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The archive is everywhere

ESSAY

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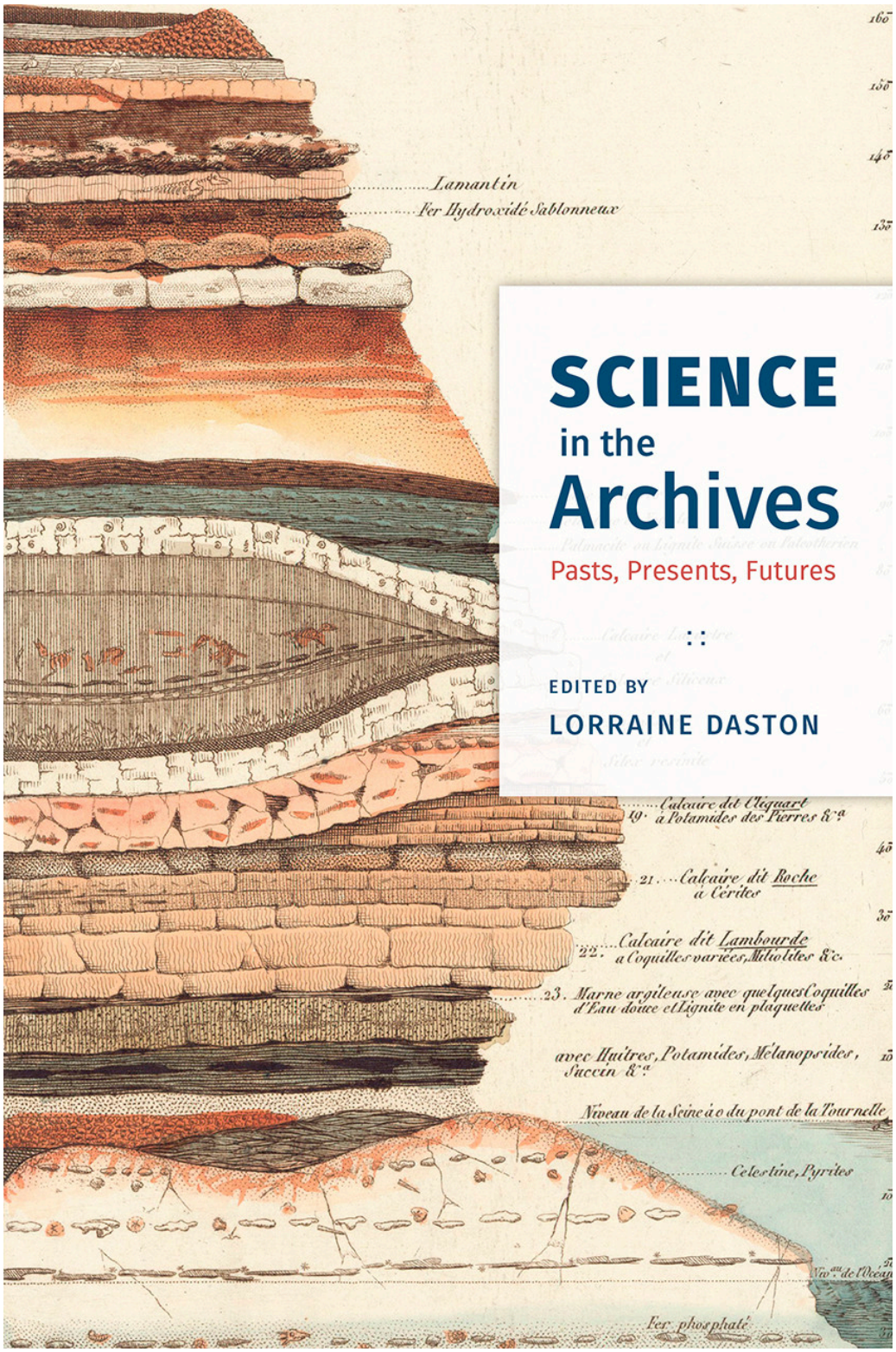
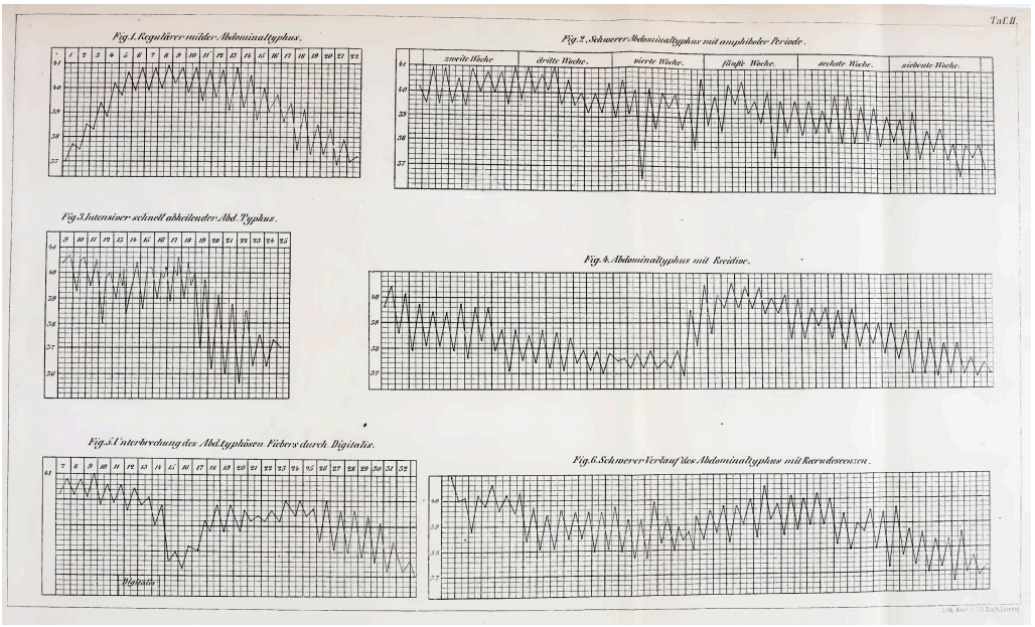
The archive has been, is and will remain a vital resource in the production of medical knowledge. We simply need to open our eyes to it.



New book: Lorraine Daston, ed. Science in the Archives. Pasts, Presents, Futures. *Chicago, IL: University of Chicago Press, 2017*

What is an archive? One's thoughts tend to turn to monumental library buildings with acres of shelves, rolling ladders and row upon row of dusty, leather-bound volumes, places where time has stood still, or to hidden basement archives with handwheel-locked shelves for safeguarding national treasures from fire (or flood?) – and to archivists painstakingly coding fragments of information in complex systems of letters and numbers for the benefit of future generations of researchers.

Is a library the same as an archive? The two tend to overlap, but a library is usually characterised by its collection of published printed and non-printed material – primarily books. However, all that is changing – at the new Tøyen Public Library in Oslo, for example, one can borrow tools like jigsaws, hammer drills and angle grinders. An archive, on the other hand, is often regarded as a collection of unique and rare material that is not published, such as handwritten letters, architect's drawings, and map collections.



Type curves from C.A. Wunderlich's book "Das Verhalten der Eigenwärme in Krankheiten" (Leipzig: Verlag von Otto Wigand, 1870). Wunderlich (1815–77) was Professor and Medical Director at St. Jacob's Hospital in Leipzig. The curves represent idealised courses of fever and illness in typhoid fever. Open Knowledge Commons and Harvard Medical School

What happens if we broaden our perspective about what an archive is? That is the question that was the starting point for a newly published anthology, *Science in the Archives. Pasts, Presents, Future*s, edited by Lorraine Daston, Professor of the History of Science at the Max Planck Institute in Berlin. She has also written the introduction and last chapter of the book.

The 12 chapters in the anthology take issue with the myth that archives belong to the historians or that archival research is historical research. According to Daston, this notion has led to archival research in disciplines other than history having been largely ignored. As an object of research, the archive and archival work have not had the same attention and status as, for example, research into the research methodology and practice of the natural sciences, with laboratory practice, for instance, having become a core research field in science and technology studies (1). This publication is therefore also an attempt to open up new fields of research and ways of approaching and understanding research practice.

From clay tablets to #foodporn – an archivarian

moment

The contents of archives – what people have considered worthy of preservation – have varied from time to time and from place to place. They can be anything from Mesopotamian clay tablets, Egyptian papyrus rolls, medieval parchments, fossils of extinct animals, piles of official documents or leather-bound first editions, to microfilms, hard disks and digital databases.

According to Daston, a shift took place in the mid-19th century. Until then, people had preserved only highly selective material (such as the thoughts of important philosophers and astronomical observations in line with the best mathematical models of the day), but there was now an increasing tendency to preserve "everything". Science was in a state of flux and it must be possible to counter and test new theories. This required the existence of flexible and comprehensive archives. And with that, the nightmare of "too much information" was born.

Daston claims we are in the midst of what she calls "an archivarian moment". On the one hand, we are overwhelmed by all the information we have available to us, while on the other we fear that everything could disappear at the stroke of a key ("the page you are looking for no longer exists", incompatible data storage systems, cyber-attacks).

What will the archive of the future look like? How can we assure continuity between past, present and future when everything is in flux? With this as the point of departure there is an insistence that we must broaden our horizons and look at archival practices across time and fields of research – move our attention from the research object to the practices themselves.

A microfilm reader, from a photograph taken in 1953 at the National Archives of Norway when they were housed at Bankplassen 3, where the National Museum - Architecture now stands. The microfilm reader is now on display in the National Archives' reading room at Sognsvann in Oslo. Photo: Leif Ørnelund / Oslo Museum / *Byhistorisk samling (CC BY-SA)*

Daston highlights the fact that practices have their own chronology and rhythm; they follow a slower, more robust tempo than the individual empirical findings – discoveries are constantly being made, but practices change more slowly. Statistical significance testing is one example of a practice which has shaped and which dominates clinical medicine research. Daston believes we could think similarly about archival practice. It follows its own extremely slow tempo. If we recognise that, it enables our thoughts about the archive to reach across disciplinary traditions and down the centuries.

*Science in the Archives. Pasts, Presents, Future*s contains contributions from very different scientific disciplines, from the use of fossils as an archive of palaeontology, to archives of digital representations of ourselves. If we understand ourselves as a bundle of historical memories – where have I come from, what have I achieved? – what implications will a growing tendency for digital logging and sharing then have for our understanding of ourselves?

Just think what we are confronted with daily on various digital media – everything from our own pulse data from the last exercise session, a screenshot of an amusing text message, a photo from our most recent restaurant visit (there are currently some 140 million food photos under the hashtag #foodporn on Instagram) to video logs where we share a personal experience. Do digital traces remember better and more truthfully than our own memory? If we think of the self as an archive, is, then, a digital archive a truer representation of ourselves?

Endless archives

Two of the chapters are directly connected with problems that are relevant for medicine. One of these chapters, written by the science historian Cathy Gere, deals with examples where research scientists have investigated the genome of geographically isolated minority groups in order to find the cause of diseases and of human evolutionary history. In 1989, for example, researchers at Arizona State University obtained DNA from the indigenous Havasupai tribe.

The Havasupai, who have probably lived in the Grand Canyon in the USA for more than 800 years, are known for their very high incidence of diabetes. The researchers wanted to investigate the genetic basis for the disease, but also wanted to study the genetic causes of schizophrenia. That was not what the Havasupai themselves wanted. Using vaguely worded declarations of consent, the researchers nonetheless gained access to the genetic material. When it later became evident from 15 research articles that things other than diabetes had been studied – for example inbreeding and schizophrenia – the Havasupai sued the researchers.

Gene banks from all over the world store backup copies of their seed collections in the Global Seed Vault on Svalbard. Situated at an altitude of 130 metres to protect against rising sea levels, the Vault consists of three separate storage halls 120 metres deep inside the mountain, maintains a temperature of -18 °C, and is earthquake-proof. In 2015 it contained 860,000 seeds from 64 different gene banks. Photo: Matthias Heyde, Ministry of Agriculture and Food / Flickr (CC BY-ND)

If we consider the human genome as archive material and the Havasupai tribe's collective genome as an archive, this case shows how many ethical problems and challenges may arise when we establish new, endless archives without a clearly defined purpose. New material generates new research questions, which raise new ethical problems.

This case also illustrates how problematic it is to use data for purposes other than those originally planned (and for which consent was obtained). Even if we have declarations of consent stating that archived biological material may or may not be used for future research, we cannot get away from the fact that archiving human biological material opens up room for interpretation. As Gere points out, the storage of biological material obligates the population in ways that are impossible to foresee when consent is given.

Biobank as archive

The case of the Havasupai is also illustrative of the on-going discussion in Norway about biobank storage of blood samples from screening of newborns. In June 2017 The Ministry of Health and Care Services sent out for consultation a proposed amendment to the Treatment Biobank Act that will allow the blood samples taken in connection with newborn screening tests to be stored in perpetuity.

This raises a number of questions of principle. Among other things, the consultation proposal refers to the Health Research Act, which states that the Regional Committees for Medical and Health Research Ethics (REC) may

decide that human biological material collected through diagnosis and treatment may be used for research purposes without the patient's consent being obtained.

The Act presupposes that the research in question is of "significant interest to society and the participants' welfare and integrity are assured". Furthermore, "the patient must have been informed in advance that in some cases human biological material may be used for research and must have been given the opportunity to refuse to be involved in research on human biological material" (Health Research Act, section 28). The problem is that it is very difficult for the population to understand and identify in advance, at the moment they have the opportunity to refuse consent, what sort of research this may be (2).

An archive containing Norwegians' DNA – with a near 100 % take-up rate for the screening programme – would be a valuable source of future research into diagnosis and treatment of a number of diseases and obviously of significant interest to society.

One of the largest anthropological archives in Europe is De Schreinerske Samlinger, named after Kristian Emil Schreiner (1874–1957), Professor of Anatomy and Head of the Institute of Anatomy at the University of Kristiania/Oslo 1908–45. Under his leadership, the physical-anthropological characteristics of the Norwegian population were mapped. Schreiner was particularly interested in the Sami population and collected considerable quantities of material comprising Sami skulls and bones. In recent years, this material has become controversial, with demands for it to be returned to the Sami people and reinterred. The skeletons of 94 Skolt Sami, which in 1915 were dug up in the community of Neiden in Finnmark, were returned and reinterred in 2011. The management of the Sami section of the collection now falls under the Sami Parliament (Sametinget). Photo: John Petter Reinertsen / Samfoto / NTB scanpix

But what happens when the interests of the majority conflict with those of minorities? The Havasupai case demonstrates that other interests can suffer when society wants information that can pose a threat to vulnerable minorities. Gere shows that colonial abuses of power still occur in a postcolonial world, also in medical research.

She also cites several examples of the science of evolutionary genetics – which after the Second World War sought to banish the ghost of eugenics – having fallen into exactly the same trap when researchers sought to identify "pure genomes" in an increasingly globalised and modern world: "the settlement against Arizona State University in the Havasupai case exposed the inadequacy of the discourse of science as a simple antidote to racial prejudice" (p. 218). This example shows that archiving is in no way a neutral, non-political exercise.

Medicine is an art of forgetting

The other chapter is by the medical historian J. Andrew Mendelsohn. In Mendelsohn's words, medical knowledge has been as much an art of forgetting as an art of memory.

The fever curve is one example: over two million body temperature recordings from patients in a Leipzig hospital in the mid-19th century have disappeared. The documents were not deemed worthy of preservation, and were discarded after use. All that remains is the type curve. It was not the plotted averages of data that were retained, but idealised presentations of the shape of the fever curve in various diseases. Seeking to remember everything – total recall – would mean chaos and paralysis in the encounter with the individual patient.

And this is an important point in Mendelsohn's argument: medicine was theoretical knowledge that was practised in real life – a very distinctive kind of practice. Unlike archival practice in astronomy, where meticulous and accurate descriptions and calculations have been preserved, medical knowledge has been dependent on idealising knowledge to make it applicable in practice.

In the space between the generalised and the particular – the application of generalised knowledge in the encounter with the patient and the synthetisation of generalised knowledge from the patient encounter – a type of information arises that medicine has taken particular care to archive: the case report. Mendelsohn's interest does not lie in examining how these case reports were written, but how they have been used and archived – and how this practice has been formative for the production of medical knowledge.

For if there is one thing doctors have done, it is to record and describe – and to read what others have written and described. The production of medical knowledge has been driven not only by observations and experiments, clinics and laboratories, but rather the development of medical knowledge has very much consisted of research in libraries – archive research. This has been empirical research. The point is that modern medicine is not only characterised by knowledge produced in the laboratory or at the hospital bedside. The birth of modern medicine is just as much associated with the art of printing and archiving.

Wax casts (moulage) have been used to create medical archives for educational purposes since the Renaissance, and there are a number of large historical collections in Europe. This is from a collection in Edinburgh. Photo: Centre for Research Collections University of Edinburgh/ Flickr (CC BY-SA)

In the 17th century, physicians organised case reports chronologically in so-called centuriae – knowledge banks for future physicians containing case histories that could not be explained. When, in the second half of the 18th century medical journals began to be published, they were very much focussed on descriptions of unusual case histories. Mendelsohn's point is that the knowledge arose in the archive because it was as much an archive of what we *didn't* know as what we knew. It was a prerequisite for the generation of new knowledge.

The archiving, systematisation and organisation of medical knowledge has been going on for centuries. There is therefore reason to question the notion that evidence-based and systematic knowledge is something we invented in the last half-century. Powerful data tools in modern epidemiology and sophisticated comparison practices (in randomised, controlled studies) have, of course, changed medicine. Nevertheless, if we follow Mendelsohn's argument, there is

more that unites than divides present-day production of medical knowledge from that of the past. "Digital, electronic medicine so far looks much like the old paper library medicine" (p. 104).

The open archive

The case report does not perform the same function today as it once did. It has landed at the bottom of the pyramid of what is deemed good research. Yet there is nothing to indicate that medicine has lost interest in this type of information.

We continue to publish case reports in the Journal of the Norwegian Medical Association. The number of English-language journals dedicated to publishing medical case reports rose from only a few at the turn of the millennium to more than 150 in 2015 (3). This is also as a result of rapid changes in the world of publishing. Many of these journals have dubious publishing practices. Nevertheless, case reports still have a part to play in disseminating unusual observations, for example drug interactions (4).

The editorial staff of this Journal recently had a discussion as to whether we could publish a case report where the authors had been unable to identify what the patient was suffering from. Would a decision not to publish the case report not break with what Mendelsohn believes has been a vital function of the archive in the development of medical knowledge – namely to keep the archive open?

The archive is key to the production of knowledge in a number of disciplines – including medicine. If we are to understand how, we need to broaden our understanding of what an archive is. Equally important is to draw attention to archival research practices. The archive is so much more than a pile of dusty old things.

LITERATURE

1. Bauer S, Heinemann T, Lemke T. red. Science and Technology Studies. Klassische Positionen und aktuelle Perspektiven. Berlin: Suhrkamp Verlag, 2017.

2. Høring - forslag om varig lagring av blodprøvene i nyfødtscreeningen. Høringssvar fra Senter for medisinsk etikk, Det medisinske fakultet, Universitetet i Oslo 4.9.2017. https://www.regjeringen.no/no/dokumenter/horing---forslagom-varig-lagring-av-blodprovene-i-nyfodtscreeningen/id2555376/?uid=c39471a3-785f-44d8-8ac4-dda4eff640bf# (4.10.2017).

3. Akers KG. New journals for publishing medical case reports. J Med Libr Assoc 2016; 104: 146 - 9. [PubMed][CrossRef]

4. Nylenna M, Breivik N, Heiberg A et al. «Et høist mærkeligt Sygdomstilfælde hos flere Sødskende»–en norsk førstegangsbeskrivelse fra 1830? Tidsskr Nor Legeforen 2016; 136: 437 - 40. [PubMed][CrossRef]

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