Medical Records Redefined:

The Value of the Archival Record in Medical Research

by

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Abstract

Increasing the visibility and societal understanding of archives is an important task given the struggle archives have to show their worth and attract a larger and more diversified group of researchers. Researchers in the field of medicine often already have the visibility that archivists seek and, within that field, those who use archival sources in their investigations may be able to increase their audience's awareness of archives. Consequently, reaching out to these researchers is an important step in increasing archival consciousness and appreciation. Learning about what they value in archives and how they use them are equally important.

For a medical researcher, archives can provide important data for studies. This thesis analyzes key medical research uses of archives over the last forty years. As will be highlighted here, medical researchers have used archival records to study the effects of malnutrition, trauma, and environmental conditions on health. Greater awareness of the contribution of archival materials to medical knowledge and better health care has the potential to change public perceptions of archives. This medical research provides concrete examples of the value of archives to the central contemporary concerns of society. It dispels the conventional view that archives are peripheral to those concerns. Instead, it underscores the importance of archival work and the need to support it. The archival record is fluid. It has different meanings for different people at different times. Archivists must adopt a fluid perspective on value when they seek to increase their visibility and attract new users to their institutions. Records used in medical research may not have been created with that in mind. Thus by re-imagining what the medical record can be, this thesis hopes to contribute to this important process.

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Finalement, je tiens à remercier ma famille: mes parents Maurice et Denise, mon frère Jocelyn, ma sœur Carmen et ma belle-sœur Cristina pour leur soutien sans faille. Merci à vous, ainsi qu'à ma famille élargie, les Vielfaure et les Gallant, qui m'a montré à plusieurs reprises ce qu'on peut accomplir lorsqu'on se met à la tâche et lorsqu'on fait ce qu'on aime. Merci infiniment!

Cette thèse est dédiée à la mémoire d'Alice Vielfaure (1930-2014)

La plus grande fan de mon écriture et une de mes sources constantes d'inspiration, tout comme Raoul, Lorette, Madeleine et Alban.

Introduction

In 1995, an expert team that included a physician, a medical examiner and a medical photographer took it upon itself to try to solve a medical mystery. Their subject of interest was a patient who suffered from multiple health problems. The patient presented with gastrointestinal problems, nosebleeds, respiratory difficulties, depression, anxiety, and aches and humming in his ears. He often felt very weak, which left him bedridden on various occasions for days at a time. He was treated by various physicians, none of whom could determine what ailed him or how to ease his pain. His unknown illness and the quest to solve the mystery captured the attention of many, including American media outlets such as CBS, ABC and NBC, the *Los Angeles Times*, the *Chicago Tribune*, the *New York Post*, and the *San Francisco Chronicle*. News sources in other countries such as Italy, England, and Japan were also interested in the work of these investigators.

Working with the team of medical professionals was an international network of people from an entirely different field. This group could help the team locate information that the patient himself could not offer due to two key problems of communication. First, the patient was deaf. Second, the patient died over 150 years before this investigation began. The subject of the investigation was Ludwig Van Beethoven and the professionals who helped uncover information important to the investigation were archivists.[1]

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[1] Russell Martin, Beethoven's Hair: An Extraordinary Historical Odyssey and a Scientific Mystery Solved (New York: Broadway Books, 2000); François Martin Mai, Diagnosing Genius: The Life and Death of Beethoven (Montreal and Kingston: McGill-Queen's University Press, 2007).
[2] Martin, Beethoven's Hair, 6.
[3] Ibid., 272.
[4] Ibid., 84, 197, 210, 211, 213, 230, 275.
[5] Ibid., 235.
[6] Ibid., 236.

Ira Brilliant (a collector of Beethoven memorabilia and a retired member of the real estate profession) and Dr. Che Guevara ("fellow Beethoven zealot" and physician) obtained a locket at an auction in London in 1995 that contained a lock of Beethoven's hair.[2] They believed that DNA testing might reveal insights into Beethoven's health and the cause of his death. Before their retrospective diagnosis of Beethoven could be carried out, they needed to verify that the hair did indeed belong to the composer. To do so, they needed to trace the provenance of the hair and the locket that contained it.

The locket could be traced from Beethoven's deathbed in 1827 to Cologne in 1911 when it was refurbished. At that point, a note was inserted into the locket which identified the hair inside as Beethoven's. The date of refurbishment and the name of the man who cut the hair, Ferdinand Hiller, was also included in the note. The journey of the locket is unknown from 1911 until 1945, when it reappeared in Denmark as it was offered to a doctor by a Jewish refugee whom he treated. The daughter of this doctor put the locket up for auction in 1995. DNA testing comparing the hair to a bone fragment from Beethoven's skull would only come six years after the investigation began.[3] In the meantime, Brilliant turned to archives and archivists in Cologne, Bonn, Frankfurt, and Düsseldorf, as well as Denmark, Sweden, Israel, and the United States to uncover more information about the hair's provenance.[4] These archivists helped identify descendants of Ferdinand Hiller and trace their lives – their marriages, children, careers, military activities, name changes, and emigration – from 1911 to the present.

The archival sources utilized by Brilliant and Guevara are described in a book by Russell Martin, which was made into a documentary by the BBC. The investigation into

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[2] Martin, Beethoven's Hair, 6.
[3] Ibid., 272.
[4] Ibid., 84, 197, 210, 211, 213, 230, 275.

Beethoven's cause of death gained international notice, even more so when Brilliant and Guevara revealed that the hair contained "forty-two times the lead average contained in the controls."[5] A retrospective diagnosis of lead poisoning was in line with Beethoven's symptoms, including gastrointestinal symptoms, headaches, jaundice, "partial paralysis of extensor muscles of the arms and legs [...] visual deficits and a progressive loss of hearing."[6]

Beethoven could have been suffering from lead toxicity for over twelve years before he succumbed to his illness because lead is absorbed in the bones when it is first ingested and then steadily released and circulated throughout the body in the years that follow. His diet may have caused him to ingest lead as he drank "plumbed wine." Lead was used to cut the bitterness of wine in his time. While not at toxic levels, the built environment in Vienna may have contributed to his lead toxicity in minimal amounts, as water pipes were "lead-soldered."[7] His lead toxicity may have also engendered psychiatric symptoms. Author François Martin Mai identified references to feelings of torment and grief, and thoughts of suicide in letters written by Beethoven, which were brought on by the loss of his hearing.[8] The connections drawn between Beethoven's health and his diet, environment, and psychological trauma are just a few areas that were demystified by Brilliant and Guevara's work, and aided by their archival contacts.

The story of Beethoven's hair is a fitting anecdote with which to open the discussion of the ways in which medical knowledge benefits from archives and how archives benefit from researchers who utilize them for medical purposes. Within the story

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[5] Ibid., 235.
[6] Ibid., 236.
[7] Ibid., 235.
[8] Mai, Diagnosing Genius, 107.

of Beethoven's hair, is a story of historical research that uses archives and generates interest in contemporary health care research. The story has interested people coming from the field of medicine and science, history, and music. It has also gained the attention of the general public. These people are "indirect users" of archives – those who "may never enter an archives or archival Web site, but benefit nevertheless from archival information by using the many and varied products arising from their direct use."[9] The book and the work of Brilliant and Guevara have been referenced in scholarly articles and popular sources alike.[10]

Coverage of the health care related research benefits in such a diverse set of sources might help archives defeat an anonymity that the profession finds hard to shake. Important to note, however, is how archives are being viewed. In the best of cases, the archival sources that have informed or enhanced our understanding of health have been described as valuable, unique, even revolutionary which, in turn, reflects positively on the institutions holding such records.

In other cases, hurdles faced by researchers such as access barriers or inadequate research facilities can reflect poorly on archives if their users make mention of the obstacles they faced when working with their sources when they publish their work. In tracking the provenance of Beethoven's hair, readers learn from Russell Martin that

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[9] Mary Jo Pugh, *Providing Reference Services for Archives and Manuscripts* (Chicago: Society of American Archivists, 2005), 37, 40.

[10] See for example: R.J. Shamberger, "Validity of hair mineral testing," *Biological Trace Element Research* 87, no. 1-3 (2002): 1-28; A.C. Hui, and S.M. Wong, "Deafness and liver disease in a 57-year-old man: a medical history of Beethoven," *Hong Kong Medical Journal* 6, no. 4 (2000): 433-38; Josef Eisinger, "The lead in Beethoven's Hair," *Toxicological and Environ Chemistry* 90, no. 1 (2008): 1-5; Elizabeth Lunday, *Secret Lives of Great Composers: What Your Teachers Never Told You About The World's Musical Masters* (Philadelphia: Quirk Books, 2009), 57; Deborah Hayden, "Beethoven's Hair Tells All!" *The New York Times,* January 10, 1999, 203; Martha Irvine, "Analysis: Lead poisoning may have affected Beethoven's behavior," *The Daily Courier*, October 18, 2000, 11A.

archivists at a music academy were helpful in providing other leads. We learn that another archivist in Düsseldorf provided researchers with "dedicated assistance."[11]

In other news sources about the Beethoven research, archivists are misrepresented. A few headlines in various newspapers refer to archivists when referencing physician Guevara and retired realtor Brilliant yet nothing in these articles or in Martin's book indicates why these two individuals are referred to as archivists.[12] Both Guevara and Brilliant provided funds to purchase the hairs, motivated by their shared love of Beethoven. Guevara contributed to the project by providing his medical knowledge while Brilliant spent time contacting archivists, researchers and genealogists to narrow down the provenance of the hair. So how do these qualities lead to their designation as archivists? Though we can only speculate, perhaps, among the greater public, there is an unclear sense of what archives and archivists do that continues to require the clarification this thesis attempts to provide. If these brief references are a reader's first encounter, or one of few encounters with the archival profession, and if first impressions are the most lasting, then archives need to make a positive first impression.

As observed by Tom Nesmith, such lack of awareness of archives and their uses among the general public is to the detriment of archives and archivists. Without an understanding of the value and uses of archives, it is unlikely that the public will "place enough political pressure on institutions that sponsor archives" to prompt them to provide better access to their records.[13] For "indirect users", just as for direct users, a positive

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[11] Martin, *Beethoven's Hair*, 197.

[12] "Archivists plan to study lock of Beethoven's hair," *The Tuscaloosa News* December 18, 1994, 8A; "Archivists play musical hairs with Beethoven's tresses," *Kingman Daily Miner*, December 18, 1994, 11A; "Archivists split hairs," *Times Daily*, December 18, 1994, 2A.

[13] Tom Nesmith, "Toward the Archival Stage in the History of Knowledge," keynote paper presented at the Congressor Brasileiro de Arquivologia (Brazilian Congress of Archival Science), Rio de Janeiro, Brazil, June 22, 2012.

experience with archives is crucial.[14] "Direct use" of archives triggers "multiplier effects," whereby people who are not associated with the direct users and the materials they consult are nevertheless affected by the use of archives.[15]

Archives themselves may in fact become "indirect users" of their own direct users work. Archivists can indirectly benefit from their users' research and the resulting increased visibility in many ways. They can learn from the different user perspectives. Not only might their users be better served but archives themselves may benefit from positive references in works published by their users and read by many more "indirect users," who may in turn, be encouraged to directly seek out archival records for their own purposes.[16] Those who have used archival sources to further their understanding of medical phenomena provide evidence of how they use archives, why they turn to such sources, and how they value them. What, then, do archival records offer medical research and what has been their impact? And what strengths or weaknesses do these users perceive in their research process?

The main benefit of using archives in the study of medical phenomena is the interplay between past and present that exists when using archives. The users examined in this thesis make use of retrospective information and apply new insights to the information found in archives. They are searching for information that documents past events – in some cases by following individuals throughout their lifetimes, sometimes until their deaths, such as survivors of various traumas experienced during the Second World War or by soldiers in the American Civil War. Often, this information was initially recorded for administrative purposes to document the operations of governments,

[14] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.
[15] Ibid., 40.
[16] Ibid., 37.

militaries, churches, and so on. Decades, or even centuries later, users are putting this information to uses never anticipated by the original creators of the records.

Given the limited scope of a thesis, it is impossible to undertake a comprehensive review of even most research related to health (i.e. "the condition of being well or free from disease") and medicine (i.e., "the science that deals with preventing, curing, and treating diseases") that has benefited from the use of archives.[17] Thus, the thesis will examine selected projects that have utilized archives in innovative ways and where the role and impact of archival use can be assessed. For this to occur, the use of archives within a study has to be visible.

While there are a multitude of studies and areas of medical research that may benefit from archival use, the primary purpose of such studies is to publicize and discuss their findings. Consequently, references to archival records, their use and value, as well as the institutions that house them, is sometimes absent from the final study. Fortunately, many studies, do make at least minimal reference to the archival records underpinning them, and thus allow a closer look at how and why they were used and the contribution to medical knowledge that they make.

Beyond looking at the contribution of these studies to medical knowledge, their multiplier effects can also speak to the impact of archives-based studies. While multiplier effects cannot be precisely measured, "indirect users" can be identified to some extent. For example, publications that have cited records-based studies are making use of

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[17] *Merriam-Webster*, s.v. "Medicine," accessed June 28, 2015, http://www.merriam-webster.com/dictionary/medicine; *Merriam-Webster*, s.v. "Health" accessed June 28, 2015, http://www.merriam-webster.com/dictionary/health. While these definitions are related, they are not synonymous. Medicine and medical knowledge may or may not contribute to better health, as some health issues may not be related to medical treatment. A better understanding of health, on the other hand, can contribute to medical knowledge.

archival records indirectly to support their own arguments or hypotheses. News sources are indirectly using archives to maintain or increase the interest of their viewers, readers or listeners. People who are suffering from or are at risk for illnesses that are better understood or treated through archival research are also "indirect users".[18]

The studies examined here that reveal the role of archives in generating "indirect use" and medical knowledge centre on themes of famine/nutrition, trauma and human-created physical environments. These three areas of research made use of various records, including photographs, textual and electronic records, produced by national and municipal governments, parishes, convents, universities and schools. Very few were created as conventional medical records, but can now be seen as such through their use (or redefinition) in medical research.

Each theme also highlights different benefits to using archives, and different challenges faced by the medical user group during the research process. These topics were chosen because they show how archives have been used in three of the most important areas of contemporary medical concern. Indeed, famine studies have made path breaking contributions to genetics, which is foundational in much contemporary medical research. The three research themes will be explored individually in the three following chapters.

The link between health and nutrition is an important starting point for this thesis as the use of archival sources has contributed to one of the first studies that showed a link between health problems later in life and the diet one had in early life and even in utero. Records in Holland, Sweden, England and the United States have contributed to new insights from this line of research into cardiovascular disease, obesity, schizophrenia,

[18] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.

osteoporosis, osteoarthritis, sarcopenia, and cancer. Archives used for the purpose of studying the effects of diet on health have also changed the way the fields of science and medicine look at genetic inheritance. Chapter one will explore this using fetal alcohol syndrome, malnutrition, and the trauma of famine as examples. Poor diet and malnutrition inflict a form of trauma on their victims – usually while in utero or as infants. But older children and adults also suffer other types of traumatic experiences that affect their health and that have also been studied by using archives. Chapter two will examine that aspect of the connection between medical research and archives.

The psychological and physical impact of traumatic events, such as exposure to violence in wartime or parent-child separation, has been better recognized, legitimized and treated through the use of archival sources. Illnesses such as Post-traumatic stress disorder (PTSD) have relatively short histories. However, some authors have debated that this is truly only representative of the disorder's recognized history and that it has existed for centuries but was misdiagnosed or overlooked.[19] Archival sources have allowed researchers to build longer histories of such illnesses so that they can be better understood and better treated in the future. Furthermore, archival records have also been utilized in innovative ways to help create environments conducive to healing for people suffering from trauma.

Records generated by governments, armies, churches, or universities have later contributed to the study of trauma by documenting important information about affected individuals. Additionally, archival records have also documented the environment that

[19] Edgar Jones et al., "Flashbacks and post-traumatic stress disorder: the genesis of a 20th-century diagnosis," *British Journal of Psychiatry* 182, no. 2 (February 2003): 158; R.J. Daly, "Samuel Pepys and post-traumatic stress disorder," *British Journal of Psychiatry* 143 (1983): 64-68; B. Parry-Jones and W.L.L. Parry-Jones, "Post-traumatic stress disorder: supportive evidence from an eighteenth century natural disaster," *Psychological Medicine* 24 (1994): 15-27.

surrounds the people referred to in such documents. For this reason, the final chapter of this thesis will examine the impact of human-created physical environments – focusing on where individuals live, work and migrate throughout their lives – and the ways in which archives have documented these environments.

Archives have preserved records that document the locations of power lines, for example, which in turn can provide insights into the health of people living near those areas. Records generated in war may enable researchers to draw connections between a veteran's health and his/her location when enlisted in order to then determine if the veteran was exposed to toxins such as sarin. Other records may describe closed or isolated environments and the effect that these environments have had on the improvement or deterioration of health through infectious diseases.

The examples given above have yet to be examined through an archival lens as publications related to these subjects have been written from a medical perspective. Archival theories and practices take on new meanings in the context of medical knowledge and these have been relatively unexplored. Archives have played a part, often a crucial one, in the cases which will be explored throughout the thesis. Yet the role of archives is not always acknowledged and is often underplayed.

The impact of medical knowledge gained from records-based studies is often considered through a medical perspective. This perspective considers things such as how we can live longer, better lives and avoid illnesses such as heart disease or Alzheimer's. These effects are considered when these discoveries are disseminated in books, articles, television and other media sources. The impact of these studies on archival institutions, on the other hand, remains unexplored. Research exploring medical topics through

historical/archival records serve as a concrete example of archival value and highlights the importance of archival work and the need to support that work.

The relationship between history and medicine is not new. Canadian hematologist and academic medical historian Jacalyn Duffin talks of doctors in the 1800s who looked to past practitioners of medicine as "fellow consultants" and taught medical history to their medical students because they believed the past continued to offer relevant lessons to the field of medicine. That said, Duffin also notes that this view has not always been widely held. Her book aims to stimulate new interest in the role historical information can play in addressing current medical research and health care needs.[20] The relationship between archives and medicine is not new either. *Archivaria* has published two special issues that have focused on medicine and archives. However, the first issue was comprised of articles on the types of social history of medicine that can be supported by archival research, not on the direct medical uses of archives.[21] Similarly, the second issue focused on the quality of health care or medical archives for medical historical research purposes, rather than medical research into current health care issues.[22]

This thesis will show that Duffin's concern is being addressed by the growing number of medical researchers who use historical information and that archives have played a key role in this development. The thesis will also show that medical knowledge can be gained beyond the walls of a formal medical archive. Publications exploring medical research topics have found information in government, parish, and convent records to name a few. Gari-Anne Patzwald and Carol Marie Wildt acknowledged one

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[20] Jacalyn Duffin, ed., *Clio in the Clinic: History in Medical Practice* (Toronto: University of Toronto Press, 2005), 3.
[21] Editors, "Archives and Medicine," *Archivaria* 10 (Summer 1980): 3.
[22] Barbara Lazenby Craig " 'Archives and Medicine' Revisited: Looking Out, Looking In, and Looking Ahead," *Archivaria* 41 (Spring 1996): 41.

such example in an *American Archivist* article. The authors have both worked as archivists for the "Nun Study," which has used records from the archives of the School Sisters of Notre Dame (SSND) in the United States to identify early predictors of Alzheimer's disease.

Epidemiologist Dr. David Snowdon sought to study the early predictors of Alzheimer's disease by interviewing the nuns at the SSND convent and, through informed consent and by ensuring that their records would be anonymized, he was granted access to their autobiographies, birth certificates, baptismal certificates, correspondence, academic transcripts, photographs, mission cards and records, surveys, questionnaires, death certificates, and medical records.[23] Many of these records were procured from the SSND archives, leading Snowdon to affirm that "[e]verything changed when [he] discovered the archives."[24]

Snowdon and his team of researchers found a connection between Alzheimer's and "idea density" (i.e., how many ideas were present in ten word intervals) in autobiographies written by the nuns and preserved in their archive.[25] They showed that the nuns who had written autobiographies presenting a lower density of ideas were more likely to develop Alzheimer's in later life.[26] Researchers also measured the use of "positive emotion words" and found a connection "between the expression of positive emotions and longevity."[27]

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[23] Gari-Anne Patzwald and Carol Marie Wildt, "The Use of Convent Archival Records in Medical Research: The School Sisters of Notre Dame Archives and the Nun Study," *The American Archivist* 67, no. 1 (Spring-Summer 2004): 93-97.
[24] Michael D. Lemonick and Alice Park, "The Nun Study: How one scientist and 678 sisters are helping unlock the secrets of Alzheimer's," *Time*, May 14, 2001, accessed January 8, 2015, http://content.time.com/time/world/article/0,8599,2047984,00.html.
[25] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 102.
[26] Ibid., 100-101.
[27] Ibid., 102.

Snowdon authored a book on his influential findings, part of which describes his research methods and his encounter with the SSND archives or, as he recounts it, his "rendezvous with serendipity".[28] The archivist at the SSND convent offered to give Snowdon a tour that led him to the convent's Heritage Room where he was immediately drawn to the archive:

> It was as though I had discovered a scientific study, started near the turn of the century, that closely followed a population over time, routinely collecting data and filing it away for later analysis. [...] Better yet, many of the records in the file cabinets referred to women still living right down the hall. This meant that I could begin to design a study that supplemented this retrospective information with even more valuable prospective data, simultaneously looking backward and forward in this time over their lives.[29]

Snowdon's reference to "retrospective information" is a key part of what makes archival sources useful to research focused on medical knowledge. The data is already available.

The alternative is to find subjects and collect data by watching them age. The disadvantage of that approach is that mortality does not discriminate. While the subjects age, so do those who conduct the study. Many of Snowdon's subjects entered the convent in their teens, when documentation on their lives began, and lived past the age of eighty. Had Snowdon conducted this study prospectively, meaning that he would have to find a study population in its teens and follow it into old age, he would not have reached the same findings within his lifespan.

The analysis of the Nun Study through the eyes of archivists has addressed issues of confidentiality, access, funding, arrangement, and records storage, and has provided a breakdown of the types of records used and their value to the study. Beyond the archival

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[28] David Snowdon, Aging with Grace: What the Nun Study Teaches Us About Leading Longer, Healthier, and More Meaningful Lives (New York: Bantam Books, 2001), 24.
[29] Ibid., 24-25.

insights offered in *The American Archivist*, the Nun Study is also another strong example of "multiplier effects."[30] The study was referenced in the *New York Times, National Geographic*, *The Washington Post*, and *The Wall Street Journal*, and reported on NPR and on television networks such as PBS, NBC, BBC, CBS, ABC and Discovery.[31] Snowdon's work has also benefitted authors of over 2,100 publications who have cited his work.[32]

The hype that Snowdon faced after he published his work on Alzheimer's would not have occurred without the SSND archives. Without its holdings, Snowdon would not have come to the same conclusions – conclusions that have piqued the curiosity and interest of so many. In fact, the U.S. National Institutes of Health was so interested in Snowdon's work that it committed $5,000,000 over ten years to Snowdon's study.[33] Its interest in the project stemmed from the fact that Snowdon's study provided a clearer connection between the development of Alzheimer's in later life and its predictors years earlier. Before Snowdon's research, others interested in the study of Alzheimer's had an "inadequate sense of how connected late-life health, function and cognition were to early life."[34] Snowdon's work provided them with "half a dozen factors" that could be linked to Alzheimer's in later life. [35]

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[30] Pugh, *Providing Reference Services for Archives and Manuscripts*, 40.
[31] Snowdon, *Aging with Grace*; "Publications," University of Minnesota – Nun Study, last modified on December 15, 2008, accessed October 11, 2013, https://www.healthstudies.umn.edu/nunstudy/publications.jsp (the link is no longer functional but can be accessed through the Internet Archive at https://archive.org/index.php); "Listen To What Your Writing Might Reveal," *Morning Edition*, NPR (August 24, 2010), accessed October 11, 2013, http://www.npr.org/templates/story/story.php?storyId=127211884.
[32] Citation count based on the "cited by" count from Google Scholar as of July 2, 2014 for the following publication: David A. Snowdon et al., "Brain Infarction and the Clinical Expression of Alzheimer Disease: The Nun Study," *JAMA* 277, no. 10 (March 12, 1997): 813-817; Snowdon, *Aging with Grace*.
[33] Lemonick and Park, "The Nun Study."
[34] Ibid.
[35] Ibid.

Such conclusions demonstrate that records of the past have proved valuable to the present and future. Archival records, if accessible and properly preserved, arranged and described, can provide useful data and new insights and understandings of various medical issues. Researchers have recognized this value and, consequently, multiple records-based studies have been conducted on an array of issues surrounding health.

Society is preoccupied with health and this is reflected in the media where health is an almost omnipresent topic of articles, books, and television and radio programs.[36] And so, medical researchers interested in archival research may present archives with a rich and viable source of "indirect users".[37] If the archival profession seeks to increase its visibility, this user group is worth understanding better. We need to examine this user group further to learn more about how its members interact with archives so that we can better serve them. But while we are learning about what archives can do for these users, we need to pursue a reciprocal relationship with them and ask: what can they contribute to the archival profession?

[36] Alexander Segall, and Christopher J. Fries, *Pursuing Health and Wellness: Healthy Societies, Healthy People* (Toronto: Oxford University Press, 2011), xii.
[37] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.

Chapter One: Archives and the Transgenerational Health Effects of Nutrition

At present, medical researchers are a relatively understudied user group in archival scholarship. They are not as evident in the literature as historians or genealogists. But, like these users, medical researchers are seeking out archival records to find a connection to the past and bring it forward in time. They seek similar information as other archival users, such as details relating to political, social and military history.[1] The key difference is that these user groups seek this connection for different purposes. Rather than searching for a connection to a personal family story or foregrounding the past to build an historical narrative, medical researchers are trying to find clues in the past to advance medical knowledge. Some researchers, for instance, have turned to archival sources to establish a link between fetal development and illnesses later in life to advance medical knowledge in the field of epidemiology.

Epidemiologists can use materials recording multiple generations of individuals to learn about the triggers of certain illnesses. Epidemiology studies "the distribution and determinants of health-related states or events in specified populations" and attempts "to control health problems" through its findings.[2] In certain cases, triggers of illness can occur years, if not decades, before the disease itself affects an individual. Studies have even shown evidence that the causes of certain illnesses might be activated generations before an illness is present, meaning that the experiences and the environments individuals are exposed to may trigger an illness in their grandchildren. Epidemiology

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[1] Emily Anne Croom, *The Sleuth Book for Genealogists: Strategies for More Successful Family History Research* (Baltimore: Genealogical Publishing Company, 2000), 71.
[2] Moyses Szklo, and F. Javier Nieto, *Epidemiology: Beyond the Basics, Third Edition* (Burlington, MA: Jones & Bartlett Learning, 2012), 3.

seeks to trace illnesses back to their starting points. Archival records have proven to be a valuable source for this purpose.

In fact, archival records contributed to what was referred to as "possibly the first epidemiologic study of prenatal nutrition and neural tube defects", which in turn spurred further research in the area, contributing to "one of the most important contributions of post-World War II epidemiology."[3] This line of research was set in motion by the Dutch Famine study. The study explored a possible connection between malnutrition and mental development through records generated during the Dutch Famine of 1944-1945.[4]

Also known as the Hunger Winter, the Dutch Famine occurred as a result of German retaliation for Dutch support of Allied forces. In 1944, the Dutch, under German occupation since 1940, were hopeful that the Netherlands would soon be liberated. The Allies commenced Operation Market Garden in an attempt to access the German Ruhr.[5] In a spirit of optimism, Dutch railway workers went on strike to slow down German troops and cut off their delivery of supplies. When the strike failed, the Germans responded by launching a food embargo, mainly in the urban centres of the western Netherlands.[6] The embargo lasted six weeks but once it ended in November 1944, the western regions of the country continued to be undernourished. The waterways through which food was delivered to western urban areas were frozen and unnavigable due to the cold winter. The famine continued until the spring of 1945.[7]

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[3] Ezra Susser, Hans W. Hoek and Alan Brown, "Neurodevelopmental Disorders after Prenatal Famine: The Story of the Dutch Famine Study," *American Journal of Epidemiology* 147, no. 3 (1998): 214.
[4] Ibid.
[5] John Antal, *Hell's Highway: The True Story of the 101st Airborne Division During Operation Market Garden, September 17-25, 1944* (Minneapolis: Zenith Press, 2008), 41.
[6] Stephen Devereux, *The New Famines: Why Famines Persist in an Era of Globalization* (Oxford: Routledge, 2007), 275.
[7] William A. Dando, *Food and Famine in the 21st Century Volume 2* (California: ABC-CLIO, 2012), 166-167.

Survivors of the famine and the records documenting their experiences have provided researchers with an invaluable source of information on the long-term effects of malnutrition. The records generated during and after the famine presented researchers with a unique opportunity. The Dutch famine was well documented by comparison with other famines. While the events in the Netherlands from 1944 to 1946 were exceptional, the records documenting them were not as the famine did not interrupt routine recordkeeping practices.

Based on the continued creation of records that documented the development of the Dutch population, as well as further documentation of rationing throughout the country, researchers could determine when and where the famine had occurred with precision and the information they found translated into "extensive, reliable and valid data."[8] Such information was found in population registers, hospital records, and military induction records.[9] This first study using records from the Dutch Famine was conducted by epidemiologists Zena Stein, Mervyn Susser, Gerhart Saenger, and Francis Marolla, who sought "to trace the effects in mature individuals of prenatal exposure to famine" through the use of records generated by or during the famine, and in the decades that followed.[10] Through historical records obtained from the Ministry of Defense, hospital archives, the City of Amsterdam Archives and the Central Bureau of Statistics, for

[8] Zena Stein et al., "Nutrition and Mental Performance: Prenatal exposure to the Dutch famine of 1944-1945 seems not related to mental performance at age 19," *Science* 178, no. 2062 (November 17, 1972): 708.
[9] Zena Stein et al., *Famine and Human Development: The Dutch Hunger Winter of 1944-1945* (New York: Oxford University Press, 1975), viii, 56; Nesmith, "Toward the Archival Stage in the History of Knowledge"; Gian-Paolo Ravelli, Zena A. Stein, and Mervyn W. Susser, "Obesity in Young Men After Famine Exposure in Utero and Early Infancy," *Journal of Medicine* 295, no. 7 (August 12, 1976): 349.
[10] Stein et al., *Famine and Human Development*, 54.

example, the study identified approximately 40,000 people who were exposed to the famine in utero.[11]

Each organization that allowed researchers to access relevant information ensured that the data provided to researchers was anonymized, as the researchers state in their acknowledgements that "[o]fficial agencies provided access to data with truly remarkable openness, while preserving all the safeguards for confidentiality."[12] For instance, the records supplied by the military included no names but all records pertaining to one individual shared a common serial number that could be used to track that individual across multiple records.[13]

At the time of the study, all Dutch men were drafted into the army at the age of eighteen. By the time they turned nineteen, most of these men underwent medical and psychological examinations to determine their service eligibility. Information of value to the study found in induction records included place of birth, date of birth, educational and work background, IQ test results, physical characteristics (e.g., weight and height), diseases and/or disabilities, and information on the father's line of work. Documents recording birth, emigration, and death were also used by researchers.[14] The information retrieved from these records provided "check points" through which the authors of the study could track the effects of famine in utero and early infancy.[15] These check points essentially provided researchers with a life map that traces the health progression or regression of the study participants through key moments in their lives. These check

[11] Ibid., 54, vii.
[12] Ibid., xi.
[13] Ibid., 59.
[14] Ibid., 59-60.
[15] Ibid., 56.

points are recorded through records that refer to and document the lives of study participants.

Using records that have already been created and which, in some cases, are many decades old, provides a useful alternative to longitudinal or prospective cohort studies. In prospective cohort studies, subjects are identified and gathered in the present by researchers who then keep track of participants and monitor their health in the years that follow for the duration of the study. By using data from records that have already been created, researchers can design retrospective cohort studies. A retrospective cohort study, also known as a historical cohort study, finds its starting point in the past, through records, and follows the health progression of individuals through these documents. In other cases, retrospective studies will find records documenting the health at birth or in early infancy of individuals who are still living and follow up by conducting interviews and examinations with the consent of the participants.[16]

The key benefit of retrospective studies is that the data is readily available to researchers. They do not have to accumulate data over years or decades as they study the aging process of their participants, while, as noted by Stein et al., the researchers grow old as well.[17] The Dutch Famine study, and other retrospective cohort studies provide a long-term perspective in a considerably shorter period of time. The extended period of time needed to identify early triggers has already lapsed, allowing for a faster development of hypotheses relating to the effects of famine and the discovery of many links to illnesses contracted later in life for individuals who were exposed to famine in utero. Stein et al. began considering their study in 1967 and the book documenting their

[16] F. Robert W. Fletcher, and Suzanne W. Fletcher, *Clinical Epidemiology: The Essentials, Fourth Edition* (Baltimore: Lippincott Williams & Wilkins, 2005), 82.
[17] Stein et al., *Famine and Human Development,* 61.

research process was published in 1975, meaning that they studied over twenty years of data in less than half the time.[18]

While this initial study did not find a connection between fetal malnutrition and slower cognitive development, the impact of the study is clear when looking at the subsequent research that has been done using records generated by the Dutch Famine.[19] Links between exposure to famine in utero and multiple illnesses and psychiatric disorders developed in adulthood have been identified. These studies look at the effects of malnutrition on fetuses or at early stages of infancy.[20]

Exposure to malnutrition in utero has provided evidence that showed that these early life conditions were connected to schizophrenia and anti-social behaviour, obesity, increased glucose levels, a higher likeliness of eating high-fat diets, cardiovascular disease and a tendency towards inactivity in later life. For women conceived and/or born during the famine, studies have found an increased risk of developing breast cancer and ovarian cancer.[21] Another historical cohort study showed that women exposed to famine in utero may themselves have children with poorer health, demonstrating the transgenerational effects of famine with the triggers of certain diseases occurring a full generation before an individual might be diagnosed.[22] These are simply some of the

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[18] Ibid., vi.
[19] Stein et al., "Nutrition and Mental Performance," 708.
[20] Sjoerd G. Elias et al., "Breast Cancer Risk After Caloric Restriction During the 1944–1945 Dutch Famine," *Journal of the National Cancer Institute* 96, no. 7 (April 7, 2004): 543; Richard Neugebauer, Hans Wijbrand Hoek, Ezra Susser, "Prenatal Exposure to Wartime Famine and Development of Antisocial Personality Disorder in Early Adulthood," *The Journal of the American Medical Association* 282, no. 5 (August 4, 1999): 455; Federico Lussana et al., "Prenatal Exposure to the Dutch Famine Is Associated with a Preference for Fatty Foods and a More Atherogenic Lipid Profile, " *The American Journal of Clinical Nutrition* 88, no. 6 (2008): 1648; Susser, Hoek, and Brown, "Neurodevelopmental Disorders after Prenatal Famine," 216.
[21] Ibid.
[22] R.C. Painter et al., "Transgenerational effects of prenatal exposure to the Dutch famine on neonatal adiposity and health in later life," *BJOG: An International Journal of Obstetrics & Gynaecology* 115, no. 10 (September 2008): 1243.

findings that have been discovered based on archival materials related to the Dutch famine.

For the Dutch study, the value of archival records lies in the demographic data found in the documents. Many archival materials are ideal for such purposes considering that

> one's entry into this world and his exit from it are carefully recorded, and [...] almost all important events of his life in between, such as education, marriage, military service, land ownership, church membership, payment of taxes, voting privileges, social security, insurance and numerous other items are made a matter of record.[23]

Documents such as these provide the key life moments that researchers were looking for in the Dutch study. Their birth dates confirmed whether individuals were exposed to the famine in utero. Ration records documented the food intake in different regions of the Netherlands. Military induction records supplied the authors of the study with information on health later in life and, as these records were available for many men in the Netherlands, researchers could identify illnesses that were prevalent in the study population, providing evidence of a link between gestational nutrition and health in later life. Other statistical records were used in the study and though these are kept by government organizations for purposes of administration, they were also a rich source of information to document the lives of individuals for medical purposes.

Like other users of archives, medical researchers often must bring together bits and pieces of information from various records to assemble a more complete picture of their subject. The information that researchers used in the Dutch study could be found in birth records, death records and those records that document an individual's development. Much like the practice of demography, researchers can "link together"

[23] William McCain, "The Value of Records," *The American Archivist* 16, no. 1 (January 1953): 6.

different archival materials to get closer to understanding the causes behind many illnesses.[24] As researchers for the Dutch Study noted, their need to connect relevant information from multiple sources heavily relied on preservation:

> In retrospective cohort studies, the collection of data necessary to extend the observations to earlier developmental phases is likely to be a difficult undertaking. Much depends on the chance preservation of relevant sets of records.[25]

If records related to a study participant are incomplete, the data that can be extracted from the remaining records is insufficient. That complete picture of health progression or regression that is needed to document the link between fetal development and illness later in life will be unavailable for research purposes.

Tracing the lives of a study population through multiple sources is a daunting task and it can be made more difficult when relevant material is inaccessible, because the information has not been preserved, or it cannot be found because of improper finding aids, or the records of an institution cannot be obtained due to access policies and legislation. For the Dutch study, potential participants from the city of Delft were not eligible for the study as the researchers "failed to obtain certain necessary data from that city."[26]

Though it is unclear whether all or only certain records were inaccessible, for medical research, any singular record related to an individual is not an independent item but rather, a piece of a greater puzzle that cannot be effectively understood without all its elements. The inability to access one record might mean an inability to interpret a key check point in the life of an individual. While the researchers do not specify the reason

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[24] Chad Gaffield, "Theory & Method in Canadian Historical Demography," *Archivaria* 14 (Summer 1982): 126.
[25] Stein et al., *Famine and Human Development,* 61.
[26] Ibid., 58.

why these records could not be attained, difficulty in accessing records needed by medical researchers for the purpose of compiling data is a common occurrence.

A team of researchers at Southampton University, under the direction of Dr. David Barker, encountered a similar obstacle when searching for useful data and overcame it by chance. In the 1980s, these researchers began looking for maternity records relating to early childhood. Barker was hoping to find evidence that would provide insights into the causes of cardiovascular disease. He believed that fetal conditions could be linked to heart disease later in life, but to find data that supported this hypothesis he would need records documenting the health and development of infants born over sixty years before.

The Southampton researchers found what they were searching for in the Hertfordshire Archives and Local Studies, where the records of post-natal health visits were located. In the early twentieth century, a team of nurses made visits to homes in Hertfordshire and documented the weight of infants at birth and at the age of one, as well as their overall development within that first year. The information collected by the nurses, which covers the period from 1911 through to the 1940s, was later written down in ledgers and given to the Hertfordshire county record office.[27]

Through these records, Barker and his team of researchers were able to develop the fetal origins hypothesis. Barker's findings would later be described by the National Institute for Child Health and Human Development as being one of their top "promising areas of research that will change our understanding of human disease."[28] This

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[27] David Barker, "The midwife, the coincidence, and the hypothesis," *BMJ: British Medical Journal* 327, no. 7429 (2003): 1428.
[28] Kate Yandell, "Prominent Epidemiologist Dies," *The Scientist,* September 16, 2013, accessed August 10, 2014, http://www.the-scientist.com/?articles.view/articleNo/37490/title/Prominent-Epidemiologist-Dies/.

'promising area' began with Barker's hypothesis that suggested that there exists a connection between the fetal environment and the development of cardiovascular disease later in life.[29] Thus, cardiovascular disease could be anticipated decades before any symptoms appear based on the conditions an individual was subjected to in utero. Furthermore, the study found links between smaller birth weights and type 2 diabetes, osteoporosis, sarcopenia, osteoarthritis, and obesity.[30]

These health outcomes are not as evident since they develop over the long term. The short-term effects of malnutrition on a fetus are more clearly perceptible. Such immediate consequences of malnutrition during gestation include stillbirths or death in early infancy, birth defects and low weight at birth.[31] However, when illnesses emerge decades after a birth, the dietary habits of the mother during the gestation period cannot be as easily identified as a trigger. For instance, cardiovascular disease or type 2 diabetes are both associated with poor nutritional habits and lack of exercise.

Such inactive and unhealthy lifestyles present a potential trigger for the development of illness and yet these lifestyles may themselves be triggered by earlier life events, as the exposure to malnutrition in utero has been linked to the tendency to eat more fatty foods and to be inactive.[32] A person who develops cardiovascular disease at age fifty presents researchers with fifty years worth of life events, many of which might be considered a trigger. Archival records permitted researchers, such as those at

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[29] Barker, "The midwife, the coincidence, and the hypothesis," 1430.
[30] H.E. Syddall et al., "Cohort Profile: The Hertfordshire Cohort Study," *International Journal of Epidemiology* 34, no. 6 (2005): 1234.
[31] Annie Murphy Paul, *Origins: How the Nine Months Before Birth Shape the Rest of Our Lives* (New York: Free Press, 2010): 23.
[32] Lussana et al., "Prenatal Exposure to the Dutch Famine," 1648.

Southampton University, to take a look back and find common factors shared in early life by individuals diagnosed with a common illness.

The preservation of maternity records has proved highly useful in looking to the past for common factors that might influence health. Records documenting health in early infancy have been described as being an "invaluable source of data" while "maternity records have become a valuable resource in [...] retrospective studies in epidemiology."[33] This value was recognized by researchers at Southampton who, like researchers interested in the Dutch famine, found a link between fetal and early infancy development and illness later in life.[34] For Barker and his colleagues, fetal development and early infancy were crucial check points in an individual's life. The nurses' records provided details on the first year of a child's life in Hertfordshire. As a result, the Southampton researchers were able to conclude that of the 15,000 study subjects born before 1930, 3,000 were deceased and nearly fifty percent of them had died of coronary heart disease or a related illness.[35]

By using the first year of life as a check point, researchers were able to identify a commonality that existed among a "disproportionate" amount of participants: low birth weights or a tendency of gaining weight at a slower rate in their first year.[36] The Hertfordshire records revealed that those who "weighed 5 pounds (2268 g) or less at birth" were two times more likely to suffer a "fatal heart attack" than "those who weighed 10 pounds or more."[37] Furthermore, among the study's male participants, those

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[33] M. Kemp et al., "Finding and Using Inter-war Maternity Records," *Social History of Medicine* 10, no. 2 (August 1997): 320.
[34] Stein et al., *Famine and Human Development*, 56.
[35] Barker, "The midwife, the coincidence, and the hypothesis," 1429.
[36] Ibid.
[37] Ibid.

at the age of one who weighed under eighteen pounds (8165 g) were three times more likely to develop cardiovascular disease than those who weighed over twenty-seven pounds (12,247 g).[38] Barker reveals his own astonishment that the records revealed information that essentially anticipated health outcomes over half a century before their diagnosis. He described the content of the records as "remarkable."[39] The discovery of a trigger for heart disease present at birth would not have been possible without the preservation of records such as those found in Hertfordshire.

Using archival records, medical researchers are able to apply fluidity to fixity. The information recorded in the midwives' records remained the same when consulted by Barker. Five pounds inscribed as a birth weight into a record in the early 1900s was still five pounds when Barker found the records in the 1980s. That information was established and set at the point of creation. That unchanging element of records content, however, is juxtaposed against the fluid nature of knowledge and interpretation over time. Barker can take that five pounds, etched into the record eighty years previously, forward over sixty years later, with new knowledge and a different interpretation, and examine the repercussions of that birth weight on later life health.

Barker's findings demonstrate the importance of looking at the historical background of various medical issues. Here lies one of the benefits of using archival records in the field of medicine. For the purposes of the Hertfordshire study, much of the data had been created over half a century before Barker and his team began searching for their records. This valuable source of knowledge was available in the archives. Assessing long-term health outcomes has been described as a complex process and, consequently,

[38] Ibid.
[39] Ibid.

"much infant research is [...] selective, poorly generalizable and focused on short-term outcomes."[40] As previously discussed, short-term issues of fetal malnutrition could include birth defects, low birth weight or stillbirths. However, if we extend the span of the study well into the mid-life period of the subjects, we can gain insights into the development of cardiovascular disease, type 2 diabetes, schizophrenia, cancer, anti-social behaviour, dietary preferences, and physical activity.[41]

Such insights into health provide a perfect example of the impact of archives and the need to promote such uses. However, promoting uses requires a better understanding of what a user needs and what an archival institution can do to facilitate the research process. A reality that must also be addressed is how institutions can become barriers to research. Access is a barrier that is addressed by Barker, as he has described the development of his hypothesis as a "fortunate" and "remarkable coincidence."[42] This coincidence is brought to light in his article "The midwife, the coincidence, and the hypothesis," which emphasizes the difficulty of accessing health records in its subtitle: "Finding an archive of health records is one thing – being able to talk your way into accessing them may depend on coincidence."[43]

Barker's good fortune lies in his family ties. The records of interest to Barker were intended to be inaccessible for another fifty years when Barker and his fellow researchers located them. By chance, these files include the birth records of Barker's sister, and the archivist they dealt with judged that Barker's relation with one of the

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[40] Joanna Murray et al., "Quality of Routine Hospital Birth Records and the Feasibility of Their Use for Creating Birth Cohorts," *Journal of Public Health* 35, no. 2 (2013): 1.
[41] Elias et al., "Breast Cancer Risk After Caloric Restriction," 543; Neugebauer, Hoek, and Susser, "Prenatal Exposure to Wartime Famine and Development," 455; Lussana et al., "Prenatal Exposure to the Dutch Famine," 1648.
[42] Barker, "The midwife, the coincidence, and the hypothesis," 1428-1429.
[43] Ibid., 1428.

subjects in the files would ensure that he would respect the confidential nature of the records.[44] Had Barker not found a personal link to the records, his conclusions may have never been reached.

Barker's findings have led many other researchers in the field to rethink their own theories on the triggers of cardiovascular disease and have led to further discoveries of illnesses that are potentially triggered in utero. Restrictive access policies might have delayed these advances in medicine by half a century, provided that the records were properly cared for and did not suffer wear and tear over the years that might render them useless as a source of data.[45]

Questions around access are difficult to resolve in any archival setting. Making records equally available to all interested users is not always possible. The accessibility of archival records may be limited for various ethical, legal or privacy reasons. The presence of medical information pertaining to people who are still alive can complicate accessibility, but this obstacle is not insurmountable. David Snowdon's Nun Study involved participants who were living and others who had passed away. Due to the collaborative relationship between the archivists and the researchers, the study went forward as terms were established to ensure that confidentiality was respected.

The names of the study participants were not included in any published information or presentations. Participant numbers were assigned to each study subject and used in place of names. Any names included in publications were pseudonyms. The subjects provided informed consent and signed consent forms.[46] These specifications were negotiated between the researchers, the archives staff and the sisters. As

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[44] Ibid.
[45] Ibid., 1429.
[46] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 91.

confidentiality is quite often an important component of medical research, negotiating access under terms of confidentiality is not a foreign concept to medical researchers.

While researchers strive to further their knowledge of illness to improve health overall, they are also well aware of the importance of respecting the personal health information of their study participants.[47] The examination of the Nun Study from an archival perspective by Gari-Anne Patzwald and Carol Marie Wildt provides a good example of how archivists can collaborate with medical researchers, facilitating access and exploring alternative solutions, rather than setting barriers to useful information. The authors have urged more archivists to seek out similar partnerships with their users to encourage further use and relieve financial burdens.[48]

Such collaboration might have dissuaded Barker from portraying his search for archival sources as one that ended with a stroke of good luck. While his reference to 'coincidence' is portrayed positively, possibly to elicit his readers' interest, he is in fact describing barriers to access. Thankfully, researchers were able to "talk [their] way into accessing" the Hertfordshire records in the end, leading to important discoveries in the field of epidemiology.[49]

Precisely quantifying the impact of the Hertfordshire study is no easy feat. However, an estimate can be reached if we consider "multiplier effects" and "indirect users."[50] This notion refers to a ripple effect whereby the direct uses of archives by researchers shape the way in which other individuals (referred to as "indirect users")

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[47] Dipak Kalra, et al., "Confidentiality and consent in medical research: Confidentiality of personal health information used for research," *BMJ* 333, no. 7560 (July 22, 2006): 196.
[48] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 92.
[49] Barker, "The midwife, the coincidence, and the hypothesis," 1428.
[50] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37, 40.

"think about themselves and their past."[51] Through this definition, we can include researchers who have developed their own studies and hypotheses as a result of the Hertfordshire study. The Hertfordshire records not only provided Barker with a unique opportunity, but led him to a hypothesis that clashed with the hypotheses of many physicians in his field.[52]

Barker's hypothesis supported the notion that an individual's predisposition to heart disease was determined in utero. Other researchers believed that the lifestyle of individuals, including their levels of physical activity, their smoking habits and their diets made them susceptible to heart disease. Barker's study played an important part in opening up new avenues of research and provided many researchers with a new lead to explore. One of these researchers was Dr. Janet Rich-Edwards, an epidemiologist who was initially sceptical of the fetal origins hypothesis.[53] While working on her own retrospective study, which examined a population of American nurses, Rich-Edwards made use of her data to conduct a study of cardiovascular disease and its link to birth weights, expecting that she would prove Barker's hypothesis to be false.[54]

On the contrary, her data and her findings supported his theory. Thus, Barker's hypothesis prompted many researchers, such as Rich-Edwards, to rethink their own theories. Heart disease was often considered to be an illness that for the most part affected the middle and upper classes as it was associated with lifestyle. Eating rich foods in higher quantities and spending more time being inactive while working in an office

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[51] Ibid.
[52] Murphy Paul, *Origins,* 25.
[53] Ibid., 26.
[54] Janet W. Rich-Edwards et al., "Birth weight and risk of cardiovascular disease in a cohort of women followed up since 1976," *BMJ: British Medical Journal* 315, no. 7105 (August 1997): 396; Murphy Paul, *Origins,* 26.

job, for instance, were considered potential contributors to heart disease. Barker's research unveiled something that contradicted this notion: "[t]he poorest regions of England and Wales were the ones with the highest rates of heart disease."[55]

Individuals who qualified as participants and could confirm or disprove Barker's hypothesis are also "indirect users" of archives.[56] These participants, born before 1940 in the Hertfordshire region, were contacted by the Southampton research team, which was looking for participants interested in going to clinics to accumulate follow up data. Thousands responded. Through archival research many of the study participants have reconnected "with relatives and friends they have not seen since childhood."[57] A hypothesis born out of a records-based study has led those attending clinics to feel as though they are contributing to significant findings that may one day contribute to better health for future generations.[58] They have recognized the value of Barker's study, a value that is strongly linked to the archival records that contributed to his findings.

Thus, if we consider the thousands of participants who were directly affected by this study, the researchers who have reconsidered their own hypotheses on cardiovascular disease based on the fetal origins hypothesis, the over 1,500 articles that have cited Barker's work, not to mention the current and future individuals who are or will be susceptible to cardiovascular disease, type 2 diabetes, osteoporosis, sarcopenia, osteoarthritis, obesity, and cancer, and could potentially benefit from Barker's research, the number of "indirect users" of archives is substantial.[59] This impact relied heavily on

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[55] Murphy Paul, *Origins,* 25.
[56] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.
[57] Barker, "The midwife, the coincidence, and the hypothesis," 1429.
[58] Ibid., 1429-1430.
[59] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37. Citation count based on the "cited by" count from Google Scholar as of July 5, 2015 for the following publications: Barker, "The midwife, the coincidence, and the hypothesis; D.J.P. Barker, and C. Osmond, "Infant Mortality, Childhood Nutrition,

archival records to find a connection between a mother's pregnancy and her child's health decades after birth. Another study has made use of archives to take this hypothesis a generation further, examining the connections between the health of individuals and the diet of their grandparents.

Lars Olov Bygren and Marcus Pembrey, working in the fields of preventative health and clinical genetics respectively, have considered the repercussions of an individual's diet over three generations while studying diet patterns in the village of Överkalix in Sweden. Överkalix has been described as holding the potential "to launch a medical revolution."[60] This potential manifests itself in records created by Överkalix's parish and maintained at the National Archives in Stockholm.[61] The content of parish records from Överkalix reveals information on births, deaths, and harvests that have proved to be a valuable source for the study of transgenerational effects of famine. The village is located in the remote county of Norrbotten, an area so isolated that in the 1800s its prosperity greatly depended on its crop production. The population of Överkalix experienced periods of "feast and famine" when people could be starving when crops were failing, or overeating when harvests were successful.[62]

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and Ischaemic Heart Disease in England and Wales," *The Lancet* 327, no. 8489 (May 10, 1986): 1077-1081.

[60] *Horizon*, season 42, episode 9, "The Ghost in Your Genes," aired November 3, 2005, on BBC, accessed May 25, 2013, *Horizon*, season 42, episode 9, "The Ghost in Your Genes," aired November 3, 2005, on BBC, accessed February 10, 2015, https://www.youtube.com/watch?v=fMxgkSgZoJs.

[61] "You Are What Your Grandpa Eats," *Radiolab*, WNYC (November 19, 2012), accessed March 11, 2015, http://www.radiolab.org/story/251885-you-are-what-your-grandpa-eats/.

[62] John Cloud, "Why Your DNA Isn't Your Destiny," *Time*, Wednesday, January 6, 2010, accessed October 17, 2013, http://content.time.com/time/magazine/article/0,9171,1952313,00.html.

Bygren began looking into the health of Överkalix residents in 1984.[63] To determine the effect that these dietary extremes were having on the health of the Överkalix community, Bygren chose a sampling of ninety-nine people who were born in the parish and whose parents and grandparents were documented in archival materials.[64] Archives in the Överkalix study have been described as offering "a unique opportunity" based on the level of detail found in parish records.[65] These documents recorded information on harvests for over a hundred years, which in turn provided researchers with details on annual food availability for multiple generations. Bygren's ability to reach conclusions and obtain results in a considerably shorter period of time heavily depended on the ability to find archival records. As journalist John Cloud affirmed, "You can't conduct an experiment in which some kids starve and others overeat. (You also wouldn't want to wait 60 years for the results.)"[66]

Bygren's study suggested to him some radical views on the impact of problems such as famine on the causes of illness. Taking the discussion of the effects of famine on health in later life a step further than the Dutch Study had, he was coming to the view that famine triggered genetic activity causing adverse health outcomes for both the child affected in utero and his or her children as well. These views were considered "scientific heresy" when they were initially presented.[67] However, in 2000, Bygren found compatible ideas in a paper by British geneticist Marcus Pembrey, published four years earlier, which proposed that gene activity could be influenced by a previous generation's

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[63] David Epstein, "How an 1836 Famine Altered the Genes of Children Born Decades Later," *Io9*, August 26, 2013, accessed March 2, 2015, http://io9.com/how-an-1836-famine-altered-the-genes-of-children-born-d-1200001177.
[64] Ibid.
[65] *Nova*, season 35, episode 2, "Ghost in Your Genes," aired on October 26, 2007, on PBS, accessed May 25, 2013, https://www.youtube.com/watch?v=AY5aWOgnI4U; *Horizon*, "The Ghost in Your Genes."
[66] Cloud, "Why Your DNA Isn't Your Destiny."
[67] Horizon, "The Ghost in Your Genes."

circumstances.[68] They attempted to recreate the results of the Överkalix study with other data to build more evidence. He contacted Pembrey and the two used data from a second, questionnaire-based longitudinal study to support their observations on genetic inheritance.[69] With further evidence to counter initial claims of "heresy" both researchers began publishing their findings in 2006.[70]

Bygren and Pembrey's research has significantly contributed to the field of epigenetics, a relatively recent field of medical science studying how the impact of environmental conditions on the behaviour of genes causes health problems.[71] The results from the Överkalix study and the subsequent collaboration between Bygren and Pembrey showed evidence that certain events could "leave an imprint on the genetic material in eggs and sperm" during their formation, meaning that a transgenerational effect could be set in motion when the grandmother of the individual affected was in utero or when the grandfather was on the brink of puberty.[72] Moreover, they concluded that these genetic imprints prompted by changes in diet could affect mortality in the children and grandchildren of those exposed to famine or abundance at key points in their lives, triggering "a biological chain of events that would lead one's grandchildren to die decades earlier than their peers did."[73]

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[68] *Nova*, "Ghost in Your Genes."
[69] Cloud, "Why Your DNA Isn't Your Destiny."
[70] *Horizon,* "The Ghost in Your Genes". Their collaborative work includes: Marcus E. Pembrey, Lars Olov Bygren, Gunnar Kaati, Sören Edvinsson, Kate Northstone, Michael Sjöström, and Jean Golding, "Sex-specific male-line transgenerational responses in humans," *European Journal of Human Genetics* 14, no. 2 (2006): 1590-166; Gunnar Kaati, Lars Olov Bygren, Marcus Bygren, Marcus Pembrey, and Michael Sjöström, "Transgenerational Response to Nutrition, Early Life Circumstances and Longevity," *European Journal of Human Genetics* 15, no. 7 (2007): 784-790; Lars O. Bygren, Petter Tinghög, John Carstensen, Sören Edvinsson, Gunnar Kaati, Marcus E. Pembrey, and Michael Sjöström, "Change in paternal grandmothers early food supply influenced cardiovascular mortality of the female grandchildren," *BMC genetics* 15, no. 1 (2014): 12.
[71] Cloud, "Why Your DNA Isn't Your Destiny."
[72] Ibid.; *Nova*, "Ghost in Your Genes."
[73] Cloud, "Why Your DNA Isn't Your Destiny."

The Överkalix study has influenced how Pembrey perceives personal behavior and intergenerational responsibility. Bygren and Pembrey have focused on the intergenerational effects of diet but their results could extend to other influences on genetic activity. The consequences of smoking, for example, may extend to the descendants of the smoker. Pembrey has suggested that these findings may change the lifestyles of future generations and the way we think about our personal choices:

> It may get to a point where [future generations] realize that you live your life as a [...] guardian of your genome. You've got to be careful of it because it's not just you. You can't be selfish because you can't say well I'll smoke or I'll do whatever it is because I'm prepared to die early. You're also looking after it for your children and grandchildren.[74]

The way scientists develop drugs to treat different illnesses has also been influenced by the study. Between 2004 and 2010, four epigenetic drugs have been approved by the FDA.[75] These drugs silence those genes that cause certain illnesses. With further knowledge, it is hoped that medical researchers might learn more about the functions of genes and how they relate to diseases such as diabetes, autism and cancer so that drugs might be developed to silence those genes as well.[76] It is no wonder that the Överkalix study has been described as revolutionary.

And while it is Bygren and Pembrey who have come to these revolutionary conclusions, it is the evidence – the records – which is credited with triggering the revolution.[77] Records, as inanimate articles, cannot launch such a revolution free from a user's interpretation and interrogations. However, it is equally true that Bygren and Pembrey could not have reached such powerful results without the right records,

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[74] *Nova*, "Ghost in Your Genes."
[75] Cloud, "Why Your DNA Isn't Your Destiny."
[76] Ibid.
[77] *Horizon*, "The Ghost in Your Genes."

documenting the right information. To trigger a reaction – or a "medical revolution" – both an accelerant (the records) and a spark (the interpretation) is needed.[78]

To conduct their research, Bygren and Pembrey required records that could "provide a life-course perspective" for multiple lives spanning over a century. In fact, the records used in the Swedish study have allowed researchers to track the life events of families for three generations, including births, diets and death. Through this information, the researchers could identify and further investigate patterns of health.[79] For instance, they reviewed deaths linked to type 2 diabetes in the Överkalix community and went back two generations. Using parish records, they could trace the lives of grandparents from conception until they reached the age of twenty. Through this information, they observed a pattern among the paternal grandfathers of those individuals who had died of complications related to type 2 diabetes.

Their data showed that there was a connection between the food intake of the paternal grandfather when he was on the verge of starting puberty and the likeliness of his grandchildren developing type 2 diabetes.[80] If an individual's paternal grandfather was overfed during puberty, then the individual was "four times more likely to die from an illness related to diabetes."[81]

The preservation of parish records has changed the way medical professionals think about genetic inheritance by allowing researchers to look back to the past, armed with new knowledge, and dig deeper to gain new insights and come to new conclusions. This retrospective quality of archival records has also allowed researchers to re-examine

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[78] Ibid.
[79] Ibid.
[80] *Nova*, "Ghost in Your Genes."
[81] Ibid.

previous medical diagnoses and correct them. Such work was done by Dr. Robert Karp, a pediatrician, on a previous study by Henry H. Goddard. Goddard's work, produced in the early twentieth century, studied the heredity of what he termed as "feeblemindedness."[82]

As a Eugenicist, he worked in New Jersey directing the Vineland Training School for Feeble-minded Boys and Girls. Under the assumed name of Kallikak, a family at the school became the subject of Goddard's research. He believed that the Kallikak family provided evidence of "transgenerational mental retardation, deprivation, and antisocial behavior," all of which supported his theory of "hereditary feeblemindedness."[83] He further denied any link to alcohol consumption during fetal development.

In fact, he believed that mental deficiencies could lead to alcoholism but that alcoholism did not lead to mental deficiencies.[84] At that time, while some suspected that there were consequences to consuming alcohol while pregnant, there was no conclusive evidence of a link. Fetal Alcohol Syndrome would only be identified as a disorder in the 1970s.[85] Over eighty years after Goddard published his findings, Karp was able to revisit the study with new knowledge and understanding of the effects of alcohol consumption during pregnancy.

The records of the Vineland Training School are now located at Elwyn, an organization providing services for various disabilities in New Jersey.[86] The Vineland Training School merged with Elwyn in the 1980s. Through archival records, including

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[82] Henry Herbert Goddard, *The Kallikak Family: A Study in the Heredity of Feeblemindedness* (New York: MacMillan, 1912), 117.
[83] R.J. Karp, et al., "Fetal Alcohol Syndrome at the Turn of the 20th Century: An Unexpected Explanation of the Kallikak Family," *JAMA Pediatrics* 149, no. 1 (January 1995): 45; Goddard, *The Kallikak Family*, 117.
[84] Karp, et al., "Fetal Alcohol Syndrome at the Turn of the 20th Century," 46.
[85] Kathleen Stratton, Cynthia Howe, and Frederick Battaglia, eds., *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment* (Washington, D.C.: National Academy Press, 1996), 17.
[86] Murphy Paul, *Origins,* 174.

textual records and photographs, Karp and his colleagues were able to find a rich source of information relating to the Kallikaks and other children at the Vineland Training School including:

> hemoglobin level and red blood cell count as evidence of iron deficiency; date of birth and age at measurements; anthropometric measurements, including head circumference, height, and weight; notes on parent-child interaction and parental alcohol consumption; evidence of exposure to environmental toxins; concurrent illness, such as tuberculosis, meningitis, and congenital syphilis; mention of other major preventable injuries, such as bumps to the head or early falls; and neuromuscular problems, such as seizures, tremors, or epilepsy.[87]

From this information, researchers were able to conduct a retrospective diagnosis of students at the Vineland Training School. Retrospective diagnoses involve re-examining the health of individuals after a condition has already been diagnosed (particularly when the diagnosis is thought to be erroneous), treated or after the individual has died. Their health is re-assessed using new information. In the case of the Kallikaks and residents of Vineland, the new knowledge that prompted the retrospective diagnosis was the identification of FAS as a legitimate disorder, a disorder that was not recognized at the time of Goddard's study.

Karp reviewed textual records and photographs from the Vineland Training School providing details on "maternal alcohol consumption; growth retardation; neurodevelopmental effects; and dysmorphic features."[88] Notes taken by Goddard provided information on physical characteristics, mental deficiencies and comportment that today would be linked to FAS. Goddard described evidence of learning and attention deficits, social problems, and impulsive behaviours among his subjects. However, this

[87] Karp, et al., "Fetal Alcohol Syndrome at the Turn of the 20th Century," 46.
[88] Ibid.

alone could not confirm an FAS diagnosis.[89] The behaviours he described could be caused by other things, such as an unstable family environment.[90]

The photographs provided further evidence that the Kallikaks suffered from FAS. Karp examined the facial characteristics of the photograph subjects to determine if they presented signs of FAS, including "a long upper lip, a narrow vermilion border, an absent philtrum, midface hypoplasia, short palpebral fissures, and prognathism."[91] The photographs corroborated an FAS diagnosis. Karp states that he used the photographs to balance the potential biases that may have existed in Goddard's textual descriptions. Goddard supported eugenic theories which, in Karp's opinion, coloured his interpretation of the Kallikaks.

Jeffrey Mifflin discusses historians' interpretation of photography and the importance of context provided by other record forms. He argues that the use of photographs is most effective when "context with other materials, integrated into a network of related historical traces" such as textual records or objects accompany the photograph.[92] Otherwise, he asserts that "photographs not accompanied by words or not found in a readable context are ambiguous."[93]

Karp's claims suggest that the reverse might be true. He claims that the text is in fact the ambiguous record necessitating supporting evidence in the form of another medium – the photograph – as the degree to which the text is coloured by personal bias was unclear. However, while Karp uses the photographs to counterbalance the prejudices

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[89] Ibid.
[90] Ibid., 47.
[91] Ibid., 46.
[92] Jeffrey Mifflin, "Visual Archives in Perspective: Enlarging on Historical Medical Photographs," *The American Archivist* 70, no. 1 (Spring/Summer 2007): 33.
[93] Ibid., 60.

in the textual records, he never addresses the biases existing in the photographs – a matter which has been raised and debated by various scholars.[94] Some of Goddard's photographs of the Kallikaks were retouched so that certain features were accentuated. Goddard's motives for doing so are the key area of debate as some argued he aimed to make the Kallikaks look menacing or more "feeble-minded" while others believe that the poor and grainy quality of the original photographs motivated Goddard to alter them to improve the image quality in the publication of his book.[95] Not all of the published photographs were retouched but as Karp never addresses the controversial aspect of the photographs, it is unclear how many of the photographs he examined were doctored and how this affected the results of his study.

The degree to which Karp was aware of the controversy over the photographs is equally unclear. Some of the sources addressed by Karp have made mention of the debate but Karp never addresses it himself.[96] However, if Karp was not aware of the context surrounding the creation of the photographs when he first requested them, then the custodian of the records would have a responsibility to make this apparent. This responsibility stems from the notion that records in the custody of archival institutions

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[94] See for example: Raymond E. Fancher, "Henry Goddard and the Kallikak Family Photographs: 'Conscious skulduggery' or 'Whig history'?" *American Psychologist* 42, no. 6 (1987): 585-590; Stephen Jay Gould, *The Mismeasure of Man: The definitive refutation to the argument of The Bell Curve* (New York: WW Norton & Company, 1996). Sigrid S. Glenn and Janet Ellis, "Do the Kallikaks Look 'Menacing' or 'Retarded'?" *American Psychologist* 43, no. 9 (September 1988): 742-743; Martin A. Elks, "Visual Indictment: A Contextual Analysis of the Kallikak Family Photographs," *Mental Retardation* 43, no. 4 (August 2005): 268-280.

[95] Fancher, "Henry Goddard and the Kallikak Family Photographs," 585.

[96] Gould, *The Mismeasure of Man*, 26.

can "only be understood in context, or in relation to their origins and to other documents, not as self-contained independent items."[97]

Beyond context, the use of Goddard's records also brings questions of ethics into play. While we cannot speak to Goddard's precise motives in doctoring the photos, we know that these records were created to support his beliefs in eugenics. Furthermore, while there is little literature that addresses the specific practices of the Vineland Training School, it was not uncommon for similar institutions that supported eugenic theories to practice unethical forms of treatment without the consent of those affected by them.

The use of records that document unethical or distressing histories requires both researchers and archivists to ensure that these materials are used appropriately, which requires both parties to find a balance among potentially conflicting elements. For medical researchers, objectivity must be balanced against compassion, as stated by the authors of the Dutch study:

> Medical science thrives on individual woe. Its one defense is that the knowledge garnered may relieve future suffering […] To add to knowledge rather than obscure it such work must be disinterested. It need not be without passion, care, and concern for the people whose suffering was the object of our studies.[98]

Today, many such records would come under access to information and privacy legislation that archivists would be obliged to follow.[99]

As stated by Elena S. Danielson, "the ethics of access is a thorny problem" but ultimately, "[p]apers are preserved so that they may be used."[100] For the Kallikak study,

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[97] Tom Nesmith, "Introduction: Archival Studies in English-speaking Canada and the North American Rediscovery of Provenance," in *Canadian Archival Studies and the Rediscovery of Provenance*, ed. Tom Nesmith (Metuchen, N.J., and London: The Scarecrow Press Inc., 1993), 2.
[98] Stein et al., *Famine and Human Development*, ix.
[99] Randall C. Jimerson, "Ethical Concerns for Archivists," *The Public Historian* 28, no. 1 (2006): 87.
[100] Elena S. Danielson, "The Ethics of Access," *The American Archivist* 52, no. 1 (1989): 53.

the original records were not created in an ethical context, but information created in one context can mean something completely different in a new context. Unethical records are not inevitably fated to be used unethically in the future. Arguably, Karp's work corrected a past injustice. While the eugenics movement has long been discredited, the Kallikaks specifically, had yet to be fairly assessed and diagnosed. Thus, prior to Karp's re-examination, their name was still synonymous with Goddard's work and findings. Correcting a past error – one that is discriminatory and unfounded – as Karp did with the Kallikak records demonstrates one way that unethical records can be used appropriately.

Through the use of photographs and textual records, Karp uncovered a misdiagnosis and re-analyzed data that, unbeknownst to Goddard, provided insights into FAS. Some have also suggested that Karp's work further provided a possible answer as to why FAS was not recognized until the 1970s. Goddard's views were believed to be legitimate claims when they were published and in the decades that followed, to the point where his "descriptions of 'hereditary feeble-mindedness' in the Kallikaks, were incorporated into the Nuremberg racial purity laws" during the Nazi regime in Germany and American immigration legislation in the 1910s.[101]

Goddard's conclusion that 'feeble-mindedness' led to alcoholism became a popular opinion shared by many. Consequently, it has been suggested that the false legitimacy given to Goddard's findings may have led some to believe that they had been given a sound, well-founded explanation that cognitive development could have an effect on alcohol consumption and may have delayed further consideration that the reverse

[101] Robert J. Karp and James T. Naprawa, "An Immense Consequence from the Suppressed Recognition of Alcohol Related Birth Defects, 1910 to 1973," *Paediatric Research* 43, no. 4S (1998): 49; Fancher, "Henry Goddard and the Kallikak Family Photographs," 585.

might be true.[102] The preservation of the Vineland Training School records allowed Karp to re-examine Goddard's findings with a fresh perspective at a time when eugenics theories were discredited and the effects of alcohol consumption during pregnancy were recognized and better understood.

Karp's work with Goddard's records changed their meaning and history. His study re-contextualized the photographs by not only contributing to the literature that discredits Goddard's observations and findings but further challenges them by providing a new diagnosis. Consequently, Karp has changed the records' provenance if we go beyond the "surface level characteristics" of the term and consider those factors which contribute to making the record anew once it has passed through "the archival threshold," including "readings of the records in archives by their users."[103]

Use can and should affect provenance but this brings up more questions and challenges for archivists. How should it affect provenance? How do we quantify change in provenance and differentiate between subtle and significant effects of use on provenance? How do we measure which uses are worth noting when documenting the provenance of a record? How and where do we integrate those uses into the history and description of records? These are not easy questions to answer, and they may only be answered on a case-by-case, record-by-record basis. But they are all worth considering, as each of the studies explored above have added "new layers of meaning" to the original records.[104]

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[102] Fima Lifshitz, ed., *Childhood Nutrition* (US: CRC Press, Inc., 1995), 241.
[103] Lori Podolsky Nordland, "The Concept of 'Secondary Provenance': Re-interpreting Ac ko mok ki's Map as Evolving Text," *Archivaria* 58 (2004): 147; Tom Nesmith, "The Concept of Societal Provenance and Records of Nineteenth-Century Aboriginal–European Relations in Western Canada: Implications for Archival Theory and Practice," *Archival Science* 6, no. 3-4 (2006): 352.
[104] Podolsky Nordland, "The Concept of 'Secondary Provenance,' " 153.

Record creators, such as Henry Goddard and the nurses of Hertfordshire, or institutions such as governments or parishes that document the development of individuals, have provided researchers with invaluable sources of information relating to nutrition and its effects on health. The original intentions of these record creators were not to provide future medical professionals with information on epigenetics, epidemiology or fetal alcohol syndrome. These areas of medical concepts were inconceivable when the records used in the studies examined in this chapter were originally created.

Whether the data gathered from archival records in medical studies are described as invaluable, unique or revolutionary, these studies have shown the opportunities that archives have to offer medical professionals and the significant impact that can result from them. The topic of medicine has become pervasive in the media. Whether it be through books, journals, newspapers, magazines, television, radio, or social media, people can obtain information on medical challenges, discoveries, practices, and progress in the many media outlets they encounter daily. If archivists seek to maximize the use of their holdings among medical researchers they must be active and visible to seek out potential users and bring the benefits of archival research to the attention of the public. Medical topics have already been brought to the attention of the public to a considerable degree. As such, archivists should facilitate medical research, collaborate with users and ensure that their institutions are given credit.

The works of Stein et al., Barker, Karp, Bygren and Pembrey all present evidence of archival use but proper credit is rarely given. The location of the records used as data by Karp is not mentioned in his study. That information is provided in a different source

authored by Annie Murphy Paul. Her 2010 book, *Origins: How the Nine Months Before Birth Shape the Rest of our Lives*, states that the records are located at Elwyn when she describes an interview she conducted with Karp.[105] Barker gives proper credit to the Hertfordshire county archives, but his article on the process of finding and using the records in Hertfordshire includes no footnotes or endnotes.

Not all professions rely as heavily on primary sources as others. Historians often require primary sources for research and understand the importance of citing their sources for multiple reasons, including allowing readers to have reference information to track sources relevant to their own interests, and ensure that an author's claims can be verified.[106] It is important for archivists to understand that different user groups have different grasps of information literacy, each bringing certain strengths and limitations based on how they typically use information.

Medical researchers may not typically deal with primary sources, with the exception of the data that they themselves generate. And so, they may not think about citing archival sources or may not know how to do so. Consequently, archivists should determine a user group's level of information literacy to ensure that users properly reference not only the institution, but also identify the specific materials consulted within that institution to ensure that archives are visible to readers of these studies and easily retrievable for those who are interested in consulting them.

Archivists reading these studies or hearing about them through other forms of media might very well recognize the role of archives and archivists in the process. They

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[105] Murphy Paul, *Origins*, 174.

[106] See James Lindgren, "Fall from Grace: *Arming America* and the Bellesiles Scandal" *The Yale Law Journal* 111, no. 8 (June 2002): 2195-2249, for an example of the use of citations to verify more contentious claims by a historian.

are aware of the time, resources and effort involved in preserving these records, storing them, describing them, and making them as accessible as possible. However, for those working outside the field of archives, or for whom the term archives is itself a foreign concept, the work of archivists can be taken for granted and may very well go unnoticed. To assist users who seek to publish their work to a larger public while not making certain that their primary sources are properly referenced in citations and acknowledgements is to miss an opportunity to become more visible and more valued in society.

Promoting a better understanding of the profession and the public benefits of archives is crucial but promoting those same ideas to users is as important. Archives will continue to be underappreciated and underfunded if users do not acknowledge and make visible the archival records they use and the institutions that hold those records. Archivists need to become their own "indirect users" whereby they benefit from the work done by their users through increased use and visibility, leading to a greater recognition of the value of archives and, hopefully, increased resources to better confront archival challenges such as backlogs and digital preservation efforts.[107]

But currently, the best way archives can be made visible to potential users in the field of medicine is through their current medical users. Ideally, archivists might attract more users from this field by actively seeking them out, but most often this is not how users encounter archives. Though many archivists dislike the narrative common to much news coverage of archival research of users 'discovering' materials in the archive – as it denies the role of the archivist in processing, cataloguing and making the records accessible – when reading about users finding relevant sources, the 'discovery' definition often seems to fits.

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[107] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.

To discover archives, or to "find unexpectedly or during a search" seems to perfectly describe some users' experiences.[108] Dr. Snowdon, for example, did not initially consider using archival records and may never have considered using them had he not walked by the Heritage Room during his tour, *unexpectedly* finding archival sources that would change the course of his study.[109] Dr. Barker may never have used midwife records had he not been as tenacious, spending "several years" *searching* for records of use to his study.[110] Not all users would be as dedicated in pursuit of records. Furthermore, it is difficult to deny that archives are relatively invisible if it took Barker many years to track down records of interest.

These individuals became archival users through chance encounters and exhaustive searches, but through perseverance and serendipity they managed to make archives, which were not so visible to them, visible to others. Until archivists are prepared to seek out users, rather than waiting for them to happen upon their institutions, it is important that archives are at the very least visible in the final product of a user's research. Whether they reference the institution and materials used in their methodology or bibliography, as of yet these references are the most straightforward way archivists can reach a greater number of potential medical users so that these users might grant archives greater attention.

The studies on nutrition and its effects on health development alone have generated significant attention as they have transformed the way medical scientists think about health and genetics and have allowed them to revisit and discredit past diagnoses.

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[108] Oxford English Dictionary, s.v., "Discover," accessed June 28, 2015, http://www.oxforddictionaries.com/definition/english/discover?q=Discover.
[109] Snowdon, *Aging with Grace*, 24.
[110] Barker, "The midwife, the coincidence, and the hypothesis," 1428-1429.

Archives have offered an opportunity for researchers to explore health and medicine in the past and draw conclusions for the benefit of the future.

New diagnoses have emerged in the last decades, such as FAS, but these illnesses are not emerging because people are just beginning to be afflicted by them. These disorders have simply gone undetected or unrecognized as legitimate health issues until more recently. Goddard did not consider FAS a possible disorder in his study because he did not recognize the link between alcohol consumption during pregnancy and fetal development. And yet, his data revealed evidence of FAS all the same. Goddard and the Kallikaks were gone by the time Karp found the records at Elwyn. In cases like these, it is the records that remain, that have been preserved and that are ready to be re-examined with the fresh eyes and new knowledge that have allowed researchers to uncover new information on the effects of nutrition on health.

Chapter Two: Re-Imagining the Record for Broadening the Study of Trauma

The types of malnutrition discussed in chapter one produced traumatic effects on fetal development and infants. But traumas have also affected older children and adults and, like malnutrition's effects, have also been studied by using archives. These impacts have often gone unrecognized, or not been considered a legitimate subject of study.[1] However, many researchers have questioned in recent years whether symptoms that are associated with Post-traumatic stress disorder (PTSD) today were described by past generations but in different terms, such as railway spine, battle fatigue, shell shock, or post-Vietnam syndrome. In some cases, the causes of these illnesses were disassociated from traumatic experience and instead believed to be caused by a person's weak constitution or genetic predisposition to mental illness.[2]

Today, these past statements reveal a history of misunderstandings of the effects of trauma on health. A lack of awareness of the impact of trauma led medical practitioners to dismiss symptoms of trauma, or mistreat those suffering from trauma. During the First World War, for example, some believed that soldiers pretended to have shell shock in order to be taken out of combat and that they continued to 'fake' their symptoms to receive compensation, leading some psychiatrists to propose that those "feigning" shell shock should not receive their pensions.[3] Following the Second World War, over 2,000 American veterans who suffered from psychiatric illnesses were lobotomized. These procedures were often conducted against the wishes of the veterans

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[1] Anthea Krieg, "The experience of collective trauma in Australian Indigenous communities," *Australian Psychiatry* 17, no. S1 (2009): S28.
[2] Charles R. Marmar, "Mental health impact of Afghanistan and Iraq deployment: meeting the challenge of a new generation of veterans," *Depression and Anxiety* 26, no. 6 (June 2009): 493.
[3] Hans Pols, and Stephanie Oak, "War & Military Mental Health: the US Psychiatric Response in the 20th Century," *American Journal of Public Health* 97, no. 12 (December 2007): 2136-37; Eric J. Leed, *No Man's Land: Combat & Identity in World War I* (New York: Cambridge University Press, 1979,) 185.

undergoing such procedures and with the approval of the government's Veterans Administration, which hoped that the operations would alleviate psychological symptoms.[4]

The term Post Traumatic Stress Disorder was officially recognized as a legitimate disorder in 1980.[5] Some medical professionals have debated whether the disorder has a longer history that has yet to be unveiled or whether the illness is unique to the twentieth century.[6] Dr. Jonathan Shay, for example, is a clinical psychiatrist who has identified descriptions of PTSD symptoms in works such as Homer's *Iliad* and *Odyssey,* as well as Shakespeare's *Henry IV*. This has led him to believe that these works of fiction are describing very real illnesses.[7] Similarly, archival sources have provided researchers with opportunities to examine the long-term effects of historical trauma incurred when people did not fully comprehend its causes and effects.

Archives have not only allowed researchers to better understand PTSD and other disorders caused or exacerbated by trauma, they have permitted them to substantiate the conclusions reached by others when past findings were contested. A study by Bruce Dohrenwend, J. Turner, Nicholas Turse, Ben Adams, Karestan Koenen and Randall Marshall, each coming from different fields, which include psychiatry, public health and epidemiology, made use of records from the National Archives and Records Administration (NARA) to investigate the accuracy of the 1988 findings of the National

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[4] Files detailing the procedures were found at the National Archives and Records Administration in the United States and published in the following article: Michael M. Phillips, "The Lobotomy Files: Part One: Forgotten Soldiers," *The Wall Street Journal,* December 11 2013, accessed on December 16, 2013, http://projects.wsj.com/lobotomyfiles/?ch=one.

[5] Jones, et al., "Flashbacks and post-traumatic stress disorder," 158.

[6] Ibid.

[7] Jonathan Shay, *Achilles in Vietnam: Combat Trauma and the Undoing of Character* (New York: Simon and Schuster, 2010); see chapter 10 for reference to Shakespeare; Jonathan Shay, *Odysseus in America: Combat Trauma and the Trials of Homecoming* (New York: Simon and Schuster, 2010).

Vietnam Veterans Readjustment Study (NVVRS). The latter study had concluded that based on "a representative sample of 1200 veterans [...] 30.9% had developed posttraumatic stress disorder during their lifetimes and that 15.2% were currently suffering from PTSD."[8]

The results of this initial study were contested by some who argued that the findings were inaccurate. Critics suggested that the results were swayed by "recall bias," an error that is caused by "differences in accuracy or completeness" present in recollections of study participants.[9] In self-report studies, where participants respond to a series of questions, the results are heavily dependent on the accuracy of the answers given.

Dohrenwend et al. re-examined the findings and collected data to corroborate the results by using historical records, including documents from NARA's military records, to determine "the severity of exposure to war-zone stressors."[10] To confirm a veteran's exposure to traumatic events, the authors of the study searched for references in personnel files that would support a PTSD diagnosis. For instance, any references recorded in military files about military decorations that were awarded to soldiers and could be linked to a traumatic experience were noted.

With this in mind, considering that a soldier who had been wounded in combat would receive a Purple Heart, any reference to a Purple Heart medal in a veteran's file could provide evidence of the occurrence of war experiences that could cause a PTSD diagnosis in the postwar period. Other circumstances that were considered include higher

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[8] Bruce P. Dohrenwend, et al., "The Psychological Risks of Vietnam for U.S. Veterans: A Revisit with New Data and Methods," *Science* 313, no. 5789 (August 18, 2006): 979.
[9] John M. Last, ed., *A Dictionary of Epidemiology, Fourth Edition* (New York: Oxford University Press, 2000), 153.
[10] Dohrenwend, et al., "The Psychological Risks of Vietnam for U.S. Veterans," 979.

casualty rates within the company to which a soldier was assigned, as well as a soldier's deployment overseas to Vietnam in 1968, as this might suggest a history of traumatic experiences related to the Tet offensive.

For soldiers who had described traumatic events in the initial survey, Dohrenwend et al. compared their accounts with published materials to verify their accuracy. For example, "[t]hree veterans reported attacks on air bases, which were reported in detail in a military history of Air Force actions."[11] In using published historical accounts, Dohrenwend et al. have also used archival sources indirectly. The books they have consulted have relied on primary source material, namely government and military documents.[12] Through an analysis of historical primary and secondary sources, the authors determined that the initial findings of the NVVRS, which concluded "that the Vietnam War took a severe psychological toll on U.S. Veterans" provided critics of the study with "compelling reasons to take this message seriously."[13]

Though the Vietnam War ended nearly half a century ago, this study has important implications for the present and future. The study focuses on Vietnam veterans and yet it introduces its topic by referring to the war in Iraq that began in 2003 and the postwar situation its veterans might face. Dohrenwend et al. open their study by drawing on the similarities that exist between both wars. This contrast is prompted by an article in *The New York Times* that reported that the American health care system would be inundated with Iraq veterans as

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[11] Ibid., 981.
[12] David Burns Sigler, *Vietnam Battle Chronology: U.S. Army and Marine Corps Combat Operations, 1965-1973* (Jefferson, North Carolina: McFarland & Company, Inc., Publishers, 1992), xv; Roger P. Fox, *Air Base Defense in the Republic of Vietnam, 1961-1973* (Washington, DC: Office of Air Force History, United States Air Force, 1979), 254.
[13] Dohrenwend, et al., "The Psychological Risks of Vietnam for U.S. Veterans," 982.

> one in six soldiers in Iraq report symptoms of major depression, serious anxiety or post-traumatic stress disorder, a proportion that some experts believe could eventually climb to one in three, the rate ultimately found in Vietnam veterans.[14]

Both the article by Scott Shane and the study by Dohrenwend et al. identify similarities between the Vietnam War and the then ongoing war in Iraq, including the initial belief that the conflict would be "short and decisive," the difficulty in differentiating enemy from civilian, and the lack of war fronts.[15]

With this comparison in mind, the authors of the study believe that the number of mental health cases that will come out of the war in Iraq may very well be similar to the cases that have emerged from the Vietnam War. Consequently, they recognize the value of re-examining relevant events from the past in order to gain more insight into PTSD to better treat it.[16]

As previously mentioned, the recognition of PTSD as a legitimate illness occurred five years after the end of the Vietnam War. As a result, the disorder has been described as "a legacy of the Vietnam War," one that has been characterized by depression, ill-temper, alcohol and drug abuse, family dysfunction, "misdiagnoses, delays in treatment seeking, [...] under-resourced mental health systems" and long-term psychological disorders for veterans.[17] The findings of the NVVRS, corroborated by Dohrenwend et al., have shown that these symptoms were fuelled by increased exposure to stressors in wartime such as subsequent deployments after an initial tour of duty or injuries obtained in combat.

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[14] Scott Shane, "A Flood of troubled soldiers is in the offing, experts predict," *The New York Times*, December 16, 2004, accessed April 7, 2013, http://www.nytimes.com/2004/12/16/national/16stress.html?_r=0.
[15] Ibid.; Dohrenwend et al., "The Psychological Risks of Vietnam for U.S. Veterans," 982.
[16] Dohrenwend et al., "The Psychological Risks of Vietnam for U.S. Veterans," 982.
[17] Marmar, "Mental health impact of Afghanistan and Iraq deployment," 493.

Insights gained into the symptoms of PTSD have been significantly affected by the NVVRS, which is considered to be "the first major study to measure the long term effects of combat."[18] However, had Dohrenwend et al. not been able to confirm the accuracy of the initial study when its findings were questioned, the legitimacy of PTSD and its impact on soldiers may not have been fully understood and recognized. The impact of the Vietnam War on mental health has encouraged initiatives by the United States Department of Veterans Affairs such as the provision of mental and physical healthcare at no cost to veterans for a period of five years. The work of Dohrenwend et al. on the NVVRS has also been cited by well over 550 publications, which include works on more recent conflicts and the impact of trauma in settings such as the first Gulf War, peacekeeping operations in Rwanda, as well as twenty-first century wars in Iraq and Afghanistan.[19]

The use of archival sources has played an important part in the success of this study. To prove that the NVVRS findings were accurate, Dohrenwend et al. needed to find an alternate source that was more accurate and credible than the initial data used by the NVVRS. They found this credible source in primary archival source material and secondary sources that utilized archival records. Much of the doubt that surrounded the

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[18] John F. Scott II, "Combat Veterans: Resiliency in Postsecondary Education Attainment" (master's thesis, California State University, Long Beach, May 2012), 10.

[19] See for example: Jitender Sareen, et al., "Canadian Military Personnel's Population Attributable Fractions of Mental Disorders and Mental Health Service Use Associated With Combat and Peacekeeping Operations," *American Journal of Public Health* 98, 12 (December 2008): 2191-2198; Margaret A. Gates, et al., "Posttraumatic stress disorder in veterans and military personnel: Epidemiology, screening, and case recognition," *Psychological services* 9, no. 4 (November 2012): 361-382; K.H. Seal, et al., "Bringing the War Back Home: Mental Health Disorders Among 103 788 US Veterans Returning From Iraq and Afghanistan Seen at Department of Veterans Affairs Facilities," *Archives of Internal Medicine* 167, no. 5 (March 12, 2007): 476-482; Nina A. Sayer, et al., "Reintegration Problems and Treatment Interests Among Iraq and Afghanistan Combat Veterans Receiving VA Medical Care," *Psychiatric Services* 61, no. 6 (June 1, 2010): 589-597. Citation count based on the "cited by" count from Google Scholar as of July 5, 2015 for the following publications: Bruce P. Dohrenwend, et al., "Continuing Controversy Over the Psychological Risks of Vietnam for U.S. Veterans," *Journal of Traumatic Stress* 20, no. 4 (August 2007): 449-465; Dohrenwend et al., "The Psychological Risks of Vietnam for U.S. Veterans," 979-982.

findings of the initial study stemmed from the self-reported data. The data collected depended on the credibility and the accuracy of the memories of participants.

The credibility of the subjects could be disputed for various reasons, including the possibility that the data was distorted by "anecdotes about fraudulent claims of military prowess in Vietnam by some individuals in the public eye" and by the "falsification of war-zone experiences by Vietnam veterans seeking compensation for psychiatric disability."[20] Moreover, it was argued that some participants provided inaccurate information, not wilfully, but simply as a result of difficulties recollecting events that occurred in the past. Could the results of the study be trusted if the words and the memories of its sources were faulty?

If Dohrenwend et al. wanted to corroborate the NVVRS findings, they needed to address its weaknesses. They needed to find an alternate way of coming to the same conclusions in order to reinforce the credibility and accuracy of the initial data and show that the results were not flawed or exaggerated. Their utilization of archival sources has supported notions of trustworthiness often associated with records. In part, this trustworthiness can be credited to the information recorded and fixed at the point of record creation. That is not to say that the record's meaning is static. Through re-interpretation, a record can be used and interpreted in different ways to reach new conclusions and gain new insights over time. Although the record is changed in meaning by its user's interpretation, the format, the wording and the information recorded by the creator(s) does not change.

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[20] Dohrenwend, et al., "Continuing Controversy Over the Psychological Risks of Vietnam for U.S. Veterans," 450-451.

The information recorded in the record remains as is. This quality remedied the weaknesses of memory as critics of the NVVRS suggested that memory was not a static faculty and could not be trusted to reveal accurate accounts of the war over a decade later. Thus, this 'fixed' quality of archival records has supplied Dohrenwend et al. with the evidence they needed to prove that the self-reported data was in fact accurate and that the NVVRS findings were not distorted by recall bias. The records acted as "extensions of the human memory," providing supporting evidence to support the accounts initially provided by participants of the NVVRS.[21]

The authors who have revisited the NVVRS have corroborated the incidence of PTSD diagnoses among Vietnam War veterans, demonstrating how postwar effects of trauma are worth considering, not only for those veterans who were affected in the past but also to learn more about how we can treat and heal those who may be affected today and in the future. Exploring past events to obtain new insights for the present and future has not only been useful in supporting evidence of the effects of trauma on mental health but also for the study of long-term effects of trauma on physical health. Records generated by the American Civil War have presented researchers with an opportunity to revisit the experiences of Civil War soldiers and track their postwar health. By doing so, they can collect a lifetime's worth of data on the effects of wartime trauma on "nervous and physical disease and mortality."[22]

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[21] Richard Pearce-Moses, *A Glossary of Archival and Records Terminology* (Chicago: The Society of American Archivists, 2005), 326.

[22] Judith Pizarro, Roxane Cohen Silver, and JoAnn Prause, "Physical and Mental Health Costs of Traumatic War Experiences Among Civil War Veterans," *Archives of General Psychiatry* 63, no. 2 (February 2006): 193.

The source of such information is found at NARA, which holds "well-documented military service records and objective health data over veterans' lifetimes."[23] Judith Pizarro and JoAnn Prause of the University of California Irvine's Department of Psychology and Social Behavior and Roxane Cohen Silver of the university's Department of Medicine have made use of these records to determine how trauma affected the physical and mental health of Civil War veterans in the postwar period, tracking their health from the end of the war until their death.

Through an "archival examination of military and medical records," the authors examined the extent to which the age of a soldier when conscripted, the number of deaths and injuries in his unit, and incidences of capture as a prisoner of war influenced health later in life. Relevant postwar events incorporated into the data included the diagnosis of illnesses and the age and cause of death of veterans.[24] By using archival records to collect this information, the authors found an alternative way to study the health of veterans. Other works studying similar topics have often relied on self-reported data.

As previously discussed, the reliability of such studies can depend on the questions asked and the answers received. Elements such as the presence of leading questions in a survey, or the tendency of a responder to downplay or overplay his/her symptoms can threaten their accuracy. The study by Pizarro, Prause, and Silver also benefitted from the use of archival records as the authors state that using "modern data sets" would not yield the same results.[25] The use of archives has allowed them to follow the health of veterans in the postwar period and, coupled with the information they

[23] Ibid., 194.
[24] Ibid., 193.
[25] Ibid., 199.

collected on soldiers before enlistment, the authors were able to follow their subjects from birth to death.

With this information, the authors sought to support their hypothesis that "greater exposure to death and younger age at entry" into the army would have an effect on gastrointestinal, heart, and mental health.[26] To substantiate their hypothesis, the authors collected information from multiple documents. From military records, they noted the age of enrollment and trauma history of soldiers in the Union Army. The latter was based on references to injuries, time spent as a prisoner of war, and number of deaths within the company of a given soldier.

From veteran and pension files the authors obtained a veteran's date of death and his health history. They determined the socioeconomic background of soldiers through their employment status.[27] Through the collection of data, they found that "veterans who were younger at enlistment had a 93% increased risk of developing signs of comorbid physical and nervous disease" and that men who were under the age of eighteen when they enlisted and who "witnessed more death during the war" were more likely to die at a younger age.[28]

Furthermore, the results showed that specific experiences increased the likelihood of developing specific ailments. For instance, soldiers who sustained injuries during war were sixty-four percent more likely to develop nervous conditions such as insomnia, psychosis, hysteria and paranoia. Yet, it was less probable that these soldiers would develop cardiac or gastrointestinal problems. The authors suggested that soldiers who survived the war with injuries might have been physically healthier than others as they

[26] Ibid., 194.
[27] Ibid., 195.
[28] Ibid., 198.

survived in an environment that was characterized as being "unsanitary" and so they concluded that the health of soldiers "may have acted as a buffer for physical disease" but would "not protect against the ill effects of war on mental health."[29]

Soldiers who became prisoners of war were more likely to develop both psychological and physical symptoms. They also found that this experience, combined with more traumatic events such as war wounds and a higher number of casualties within one company, led men to exhibit more illnesses later on in life, especially if they were among the younger group of enlistments.[30] The authors concluded that, although their data was collected through sources that were over a century old, their findings were still relevant for soldiers and veterans in the present as their health is similarly influenced by war.[31]

While this study presents a unique use of archives, it is in fact an example of a "multiplier effect".[32] Pizarro, Prause and Silver while using records from NARA, did not in fact obtain the records directly from the institution. To obtain what the authors described to be "the largest, most comprehensive collection of electronic Civil War data files," they looked to the Union Army Data Early Indicators of Later Work Levels Disease and Death project maintained by the Center for Population Economics at the University of Chicago Booth School of Business.[33]

The project involved seven years of data collection – whereby information was extracted from archival records held at NARA and compiled for the purpose of studying

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[29] Ibid., 198-199.
[30] Ibid., 199.
[31] Ibid.
[32] Pugh, *Providing Reference Services for Archives and Manuscripts*, 40.
[33] Pizarro, Silver, and Prause, "Physical and Mental Health Costs of Traumatic War Experiences," 194.

aging.[34] The collection of information was led by Larry T. Wimmer, Bob Fogel and Stan Engerman, economic historians who came across Union Army records while collecting data on "socioeconomic and health conditions" in North America from 1650 to 1910.[35] They were assisted in the data collection by other economists as well as medical professionals, demographers and approximately 200 students.[36]

They found that the Civil War "military records, [...] census manuscripts and published family histories" provided them with "a surprisingly complete prospective study of aging among Northern white males."[37] Furthermore, if the information found in these records could be collected and organized in a way that would allow researchers to track an individual throughout eight different types of records, they could follow the life events of each individual

> starting with national origin, wealth, and occupation of the parents of young recruits in 1861; identify each battle, disease, and hospitalization of a recruit during his wartime service; provide a documented record throughout the remainder of the veteran's life as he entered the massive pension system stemming from the Civil war; and finally conclude with later-life family structure, living circumstances, and employment found in the 1900 and 1910 federal census records.[38]

Overall, the team collected information related to 39,616 soldiers assigned to 331 companies during the Civil War.[39]

Among the types of records collected were military service records that documented pre-enlistment information on a soldier, including his employment and place of residence before the war, as well as information related to his service such as his status

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[34] Larry T. Wimmer, "Reflections on the Early Indicators Project: A Partial History," in *Health and Labor Force Participation over the Life Cycle*, ed. Dora L. Costa (Chicago: University of Chicago Press, 2003), 1.
[35] Ibid., 2-3.
[36] Ibid., 3, 8.
[37] Ibid., 3.
[38] Ibid.
[39] Ibid.

in the army, injuries obtained in battle, hospital stays, and death. Carded medical records were also collected to record information related to a soldier's hospitalization such as days spent in the hospital and physical state at admission and discharge. Surgeons' certificates provided details on veterans' weight and height, and any health problems, including disabilities. Finally, pension records provided information on postwar employment, residences, marital status, offspring, religion, and documents related to pension claims. Information on the veteran's widow or any other dependent listed on a pension was also often included. The latter two record types were described as being especially useful and distinct.[40]

The impact of this "direct use" of archives on indirect archival use is significant and has led to various "multiplier effects".[41] The data extracted from archival sources and collected by the Center For Population Economics in Chicago is freely accessible to researchers online.[42] Beyond the study of trauma by Pizarro, Prause and Silver, the data collected from NARA's holdings and compiled by the Center For Population Economics has been used in various other studies to examine health issues such as influenza, tuberculosis, and hearing loss.[43] Just like the study of trauma, these illnesses can be further explored through the use of such groupings of documents, as these become more meaningful as an aggregate for studies that seek to go beyond "individual persons or

[40] Ibid., 4.
[41] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37, 40.
[42] The data is available at http://www.uadata.org.
[43] See for example Dora L. Costa, ed., *Health and Labor Force Participation over the Life Cycle* (Chicago: University of Chicago Press, 2003); Andrew Noymer, "Testing the influenza-tuberculosis selective mortality hypothesis with Union Army data," *Social Science & Medicine* 68, no. 9 (May 2009): 1599-1608; Claudia Linares, and Dejun Su, "Body mass index and health among Union Army veterans: 1891-1905," *Economics & Human Biology* 3, no. 3 (December 2005): 367-387; Ryan K. Sewell, et al., "Hearing loss in Union Army veterans from 1862 to 1920," *The Laryngoscope* 114, no. 12 (December 2004): 2147-2153.

things."[44] Studies that investigate questions involving health seek to find information related to a relevant population and investigate the causes and/or effects of certain illnesses and experiences. For this they require various records that document many individuals across decades.

The Union Army data set has made the process of tracking individuals across various records easier by assigning each soldier an identification number so that users can retrieve data, linking information related to a particular soldier throughout the data set.[45] By linking this data, the information extracted from the files at NARA has become more easily accessed and used. The data is also more malleable, meaning that users can select specific variables that they wish to include or exclude, such as date ranges, types of records, or information related specifically to the veteran or his household if such information is provided in censuses. Users can also choose to look solely at veterans with disabilities, veterans from a specific state, and veterans with children, among other variables.

The flexibility of the data increases its potential for use as researchers from different fields can include or exclude variables depending on how or if they relate to their field of interest. The value of this format has been reflected in the Union Army data set through its use in the fields of demography, economy, and epidemiology.[46] Furthermore, these projects can broaden access. The definition of access here goes

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[44] T.R. Schellenberg, "The appraisal of modern records," in *A Modern Archives Reader: Basic Readings on Archival Theory and Practice,* ed. Maygene F. Daniels and Timothy Walch (Washington, DC: National Archives and Records Service, 1984), 66.

[45] University of Chicago Center For Population Economics, "Introduction to the Union Army Study," The University of Chicago Booth School of Business, accessed December 7, 2013, http://www.cpe.uchicago.edu/unionarmy/unionarmy.html, (the link is no longer functional but is available through the Internet Archive at https://archive.org/index.php).

[46] University of Chicago Center For Population Economics, "Union Army Data: Early Indicators of Later Work Levels, Disease and Death – About Us," University of Chicago Booth School of Business, accessed December 7, 2013, http://www.uadata.org/about/.

beyond legal notions involving access policies, freedom of information acts, or privacy acts. Access has a much more multifaceted meaning, which should include many components, including geographical access. NARA is not geographically accessible to many users. Furthermore, archives as institutions are, unfortunately, largely unknown to members of the public who lie outside of the archival community and outside of its key user groups.

Consequently, archives should take advantage of positive and concrete instances of archival use to draw in the public and increase their awareness of the value of archival work. Doing so could also increase the awareness of lawmakers, which in turn could also improve access. A lack of archival awareness among lawmakers can impede access because they might impose access restrictions while giving "little consideration to the future historical impact of records when they exempt them from release."[47]

Increasing access by extending the reach of archival records beyond the walls of the institution allows archivists to make records and their value more visible to lawmakers and the public and not only allows archives to generate use but users.[48] Through the Union Army data project, and its online accessibility, Civil War records can now be discovered, accessed and used by those working in economics, health, biology, law, and labour, for example.[49] Researchers in these fields might not think to turn to primary sources for answers and yet they might be searching for "biographical

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[47] Hugh McQuaid, "FOI Advocates Seek to Gain Access to Historical Documents," *CT News Junkie*, February 14, 2014, accessed February 15, 2014, http://www.ctnewsjunkie.com/archives/entry/historians.
[48] Verne Harris, "Redefining Archives in South Africa: Public Archives and Society in Transition, 1990-1996," *Archivaria* 42 (Fall 1996): 18.
[49] See for example, Linares and Su, "Body mass index and health among Union Army veterans," 367-387; Chulhee Lee, "Wealth Accumulation and the Health of Union Army Veterans, 1860-1870," *Journal of Economic History* 65, no. 2 (June 2005): 352-385; Peter David Blanck, and Michael Millender, "Before Disability Civil Rights: Civil War Pensions and the Politics of Disability in America," *Alabama Law Review* 52, no. 1 (Fall 2000): 1-51; Costa, ed., *Health and Labor Force Participation over the Life Cycle.*

information, known and unknown connections, events during a person's lifetime," and other details that can be found in archival sources.[50]

Such details provide researchers with information that has been produced as a result of a natural course of events. In the study of trauma, the documentation detailing the natural progression of events throughout past decades is especially useful. Manipulating circumstances under which researchers could study trauma and its impact on health would be highly unethical and so the students of trauma, much like in other areas of medical research, can learn from past traumatic events that have already occurred and that have been or can be documented.

Under such circumstances, Glen H. Elder Jr. and Michael J. Shanahan, professors in psychology and sociology at the University of North Carolina at Chapel Hill, and Elizabeth Colerick Clipp, a professor of nursing at Duke University, considered how exposure to traumatic events could impact "patterns of adaptation in human lives [...] across the life course."[51] Their data was readily available, collected by Lewis Terman, a Stanford psychologist, who in 1922 began studying gifted children.[52] Terman passed away in 1956 but his data continued to be collected by other researchers working with him and remains archived at the Stanford Special Collections & University Archives today.

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[50] Jane Stevenson, "Locah Linking Lives: an introduction," Archive hub, August 31, 2011, accessed January 30, 2014, http://archiveshub.ac.uk/blog/2011/08/locah-linking-lives-an-introduction/.

[51] Glen H. Elder, Jr., Michael J. Shanahan, and Elizabeth Colerick Clipp, "Linking Combat and Physical Health: The Legacy of World War II in Men's Lives," *American Journal of Psychiatry* 154, no. 3 (March 1997): 330.

[52] Glen H. Elder, Jr., Eliza K. Pavalko, and Elizabeth C. Clipp, *Working with Archival Data: Studying Lives* (Newbury Park, CA: SAGE Publications inc., 1993), 3.

This has prompted Elder, Shanahan and Clipp to ask "new questions of old data."[53] While Terman initially collected data to examine the development of children with high IQs, he could not predict the life events his participants would face when he began the study in the 1920s: the Great Depression and the Second World War. And so, the study collected information relevant to both events without directly considering the effects of these events on their participants. Elder, Shanahan and Clipp observed that 236 men in the Terman study went overseas to serve in the war. Among this group, thirty-one soldiers were not sent into battle while 204 soldiers were exposed to battlefield experience. One soldier was kept out of the equation of the study as researchers could not confirm his combat experience.[54]

The information gathered by Terman on these men, and the other participants who did not enlist, included records from the schools attended by the subjects. Educators, personnel, fellow classmates and the students themselves provided Terman's researchers with the needed information on an annual basis. The study also conducted multiple interviews:

> Mothers were interviewed in 1932, 1934, and 1936. Annual data collections were carried out across the 1930s, followed by five waves of data collection in the adult years, 1953, 1958-1960, 1964, 1970-1972, and 1981-1982. The follow-ups generally included interviews, health assessments, personality inventories, and fact-sheet questionnaires.[55]

At face value, this data accumulated by Terman and his team might not appear to reveal too much about the Second World War. However, Elder, Shanahan and Clipp found useful information in the details participants provided in surveys taken between 1945 and 1986.

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[53] Ibid., 6.
[54] Elder, Shanahan, and Clipp, "Linking Combat and Physical Health," 332.
[55] Elder, Pavalko, and Clipp, *Working with Archival Data,* 15.

Participants were asked about the progression or regression of their physical and mental health from one survey to the next. This included information on past hospitalizations, surgical operations, injuries, diseases, physical or emotional stress, alcohol consumption, and anxieties. When participants died, their time and cause of death were also recorded.[56] Elder, Shanahan and Clipp noted just under one hundred conditions or surgeries that were mentioned throughout the surveys. These included various types of cancer, lung diseases, alcoholism and illnesses resulting from the latter, heart disease, and type 2 diabetes.

Furthermore, two surveys sent out to participants in 1945 and 1950 provided useful information on the wartime history of participants who enlisted.[57] Researchers working on the project compiled a wartime history for the participants from the answers provided in the questionnaire, through reports and records kept by researchers and personnel, as well as correspondence between Terman and participants. These histories provided details on wartime events that could influence a soldier's postwar life, such as "witnessing injury or death or being injured, missing in action, or a prisoner of war".[58] Like the study by Dohrenwend et al., any reference to military decorations also assisted researchers in "inferring combat experiences."[59]

With this information, Elder, Shanahan and Clipp formulated new questions in hopes that the old information they examined might provide them with answers. More precisely, they wanted to know what were "the specific aspects of World War II that

[56] Ibid., 26-27.
[57] Ibid., 28; Elder, Shanahan, and Clipp, "Linking Combat and Physical Health," 331.
[58] Elder, Shanahan, and Clipp, "Linking Combat and Physical Health," 331.
[59] Ibid.

posed implications for later well being"?[60] They also sought to find out whether life experiences before the war influenced reactions to potentially distressing wartime events. This latter question was based on the hypothesis that "prewar personality factors shape the meaning of traumatic events and [...] these meanings are intimately connected to the way in which symptoms develop."[61]

To examine aspects of the participants' lives before the war, the study made use of data from a survey conducted in 1940 that included information on the employment status, income, social background, and well being of each participant. The re-examination of this data led to the discovery of a pattern among the Terman study veterans. In the fifteen years following the Second World War, a growing number of Terman soldiers who were overseas during the war or who engaged in battle began experiencing health problems, leading to "physical decline [...] or death."[62] However, this decline was more likely among soldiers who fought during the war. The study also found that the effects of war on health did not appear to be linked to the area where a soldier was stationed (for example, Europe or the Pacific) as the results did not alter among these soldiers to a significant degree. Similarly, personality traits, mainly a participant's claim to have low or high self-worth on a 1940 questionnaire, did not appear to alter the results significantly.

Many soldiers developed habits in the postwar period that may have contributed to the relatively rapid development of health problems, as well as the increased chance of dying within the first fifteen years following the war. Elder, Shanahan and Clipp found that compared to soldiers who had not experienced battle, those who had engaged in

[60] Ibid., 330.
[61] Ibid., 331.
[62] Ibid., 333.

combat were more likely to identify as "heavy or problem drinkers (38% versus 15%)."[63] Along with alcohol, the authors speculated that soldiers might also smoke more frequently after the war. These dependencies might negatively influence the health of veterans.

Secondly, soldiers might feel powerless in a war environment. Facing an unmanageable situation could aggravate stressors and have a subsequent impact on health. The authors based this theory on the works of other scholars who have proposed "that severe feelings of helplessness may be a general precursor to physical disease."[64] Some soldiers also tended to avoid talking about or thinking of their war experiences, which could lead to further health complications as a result of increased stress levels.

Finally, forty-five percent of the men who experienced degenerating health from 1945 to 1960 described symptoms affecting their stomach and/or intestines, sixty-four percent reported cardiac health issues, twenty-eight percent experienced back problems, twelve percent found that their sinuses were affected, four percent had respiratory difficulties and three percent had aches in their joints.[65] These conditions, the authors suggest, might be a result of alexithymia, a condition where one is unable to recognize, explain or deal with their own emotions. As a result, physical symptoms manifest themselves as an "outlet" for emotional distress that cannot be expressed.[66]

The authors' use of archival data has provided them with many insights into the effects of combat on postwar health. As they worked with the Terman data archives, Elder and Clipp, along with Eliza Pavalko, a sociology professor at Indiana University,

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[63] Ibid., 335.
[64] Ibid.; George L. Engel, "A Life Setting Conducive to Illness: The Giving-Up–Given-Up Complex." *Annals of Internal Medicine* 69, no. 2 (1968): 293-300.
[65] Elder, Shanahan, and Clipp, "Linking Combat and Physical Health," 335.
[66] Ibid., 336.

published a book on using data archives for research purposes. Interestingly, they have noted that archives can both limit research and inspire it. They state that researchers who hope to use a data archive should not expect to find answers to a fixed question. Archives can only yield so much.

Moreover, as was the case with the Terman archives, archival records may only provide information which reflects the original purpose for which the records were created. A user's interpretation can take that information further but said information might only be so malleable. While Terman might mention a participant's wartime injury, it is Elder, Shanahan and Clipp who consider that injury's implications on later life health as Terman never intended to explore that connection during the records' creation process. At the time Terman began his study, he could not account for the future hardships that his participants would face. He could not anticipate that they might experience financial burdens throughout the 1930s or be sent to war in the following decade.

The primary purpose of the Terman study was to follow the development of children who had high IQs. For this reason, though it might be frustrating for Elder, Shanahan and Clipp to find that the wartime status of one veteran was not noted, or that the Great Depression was not mentioned to any great degree in the records, they cannot attribute these voids in the records to oversights made by the original researchers who conducted the Terman study.[67] Terman collected the original data to investigate a specific subject and the information in the records reflect this original purpose. Researchers working with archival sources must consider that "[h]ow documents [come] into being is

[67] Elder, Pavalko, and Clipp, *Working with Archival Data,* 11.

[...] important" as their context of creation reflects the purposes for and the circumstances in which the records were generated.[68]

To confront this challenge, Elder, Pavalko and Clipp propose that investigators "maximize the fit between the research question and the data", which can be achieved by altering a research question or simply by exploring the data that is available before developing a question.[69] The strength of archival data in situations such as these is that they can inspire many research topics. While researchers should not be set on answering a specific question before they have examined a given record set, Elder, Pavalko and Clipp have reassured their readers that "[m]ere exposure to life records that span decades can provide insights on aging that shape the questions of an investigator."[70] Furthermore, while researchers could consider abandoning archival data to create their own data, tailor made for their investigation on health throughout the lifespan, they cannot gain the same insights that they could access through historical sources which might already hold answers to the questions researchers seek to investigate.[71]

The use of archival data to investigate health questions requires investigators to strike a balance in regard to the data. They must recognize both its strengths and shortcomings, exploiting the former and compensating for and working around the latter. Once this is accomplished, the benefits of using archival materials are clear and also achieved more quickly than they would have been if researchers attempted to accumulate data through a prospective study approach. The events that could generate information

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[68] T.R. Schellenberg, *Modern Archives: Principles and Techniques* (Chicago: University of Chicago Press, 1956), 13.
[69] Elder, Pavalko, and Clipp, *Working with Archival Data, 5.*
[70] Ibid., 6.
[71] Ibid., 22.

needed by researchers have already occurred naturally as a result of the Second World War.

This war has also assisted epidemiologists in their study of the effects of childhood traumas on later life health. Relying on records of past events is even more crucial to this topic since causing a traumatic event in order to study its effect on children is clearly not an option. Thus, researchers studying the impact of parent-child separation during the Second World War on health later in life have relied on the past to overcome such ethical barriers to their research. More specifically, they have turned to the events that were set in motion in Finland in 1939. Despite the tragic events of the Second World War, the records it generated have been described as providing "a unique opportunity" for researchers to examine the subject of childhood trauma "in a natural setting, involving children from various socioeconomic backgrounds."[72]

Between 1939 and 1940 and again from 1941 to 1944, Finland was at war with the Soviet Union. From November 1939 to March 1940, they were engaged in the Winter War, a conflict that ended when the Soviets seized the Finnish province of Karelia. However, in the summer of 1941, the war between the two nations resumed as the Continuation War. Finnish troops liberated the area previously captured by the Soviets. Despite their gains, the Continuation War went on for another three years, ending in 1944 with the Soviets appropriating once more the territory they had captured in the Winter

[72] Anu-Katriina Pesonen, et al., "Depressive Symptoms in Adults Separated from Their Parents as Children: A Natural Experiment during World War II," *American Journal of Epidemiology* 166, no. 10 (November 15, 2007): 1132.

War. These wars orphaned over 50,000 children and raised infant mortality rates in Finland, as proper care was difficult to come by in wartime.[73]

As the war made it difficult for Finland to offer proper care and nourishment for many children, Denmark and Sweden offered relief to these families. As a result, over 70,000 children were evacuated and sent to these countries to receive better medical care and improve their diets and standards of living.[74] Sweden took in the bulk of evacuees – approximately 65,000 children.[75] Some returned to Finland after the Winter War but were sent back to Sweden or Denmark during the Soviet offensive, near the end of the Continuation War. The end of the war marked a lengthy period of reconstruction for Finland. Approximately 400,000 people from the province of Karelia were displaced, food and other commodities were rationed through to the 1950s, and reparations amounting to $300,000,000 had to be paid to the Soviets by Finland.[76]

Dealing with the children who had been sent away further complicated the matter. For birth parents, bringing their children home was not always a good decision, as many families had been impoverished by the war or were now led by single parents due to wartime casualties. Foster parents abroad were dismayed at the prospect of giving up the children they had raised throughout the war and were considering taking steps to formally adopt their foster children. In Sweden, those who did pursue the matter through legal action did so through Swedish channels, making it difficult for Finnish parents, who did

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[73] Aura Korppi-Tommola, "War and children in Finland during the Second World War," *Paedagogica Historica* 44, no. 4 (August 2008): 445-446; Jussi Hanhimäki, "Self-Restraint as Containment: United States' Economic Policy, Finland, and the Soviet Union, 1945-1953." *The International History Review* 17, no. 2, (1995): 288; Jouko Paunio, "A Perspective on Postwar Reconstruction in Finland," in *Postwar Economic Reconstruction and Lessons for the East Today,* eds. Ruddier Dornbusch, Wilhelm Nölling, and Richard Layard (Cambridge, MA: MIT Press, 1993), 144.
[74] Korppi-Tommola, "War and children in Finland," 446.
[75] Ibid., 448.
[76] Ibid., 448-49.

not understand the language of the proceedings or could not afford legal counsel, to bring their children back to Finland.

Furthermore, the evacuated children often had little interest in returning home as many were too young when they were evacuated to remember their birth parents, their birthplace, or their native language. Meanwhile, the Finnish government did not undertake a formal plan to bring Finnish children back home and so parents who wanted to bring their children back to Finland had to take steps to do so on their own. Consequently, Sweden kept 15,000 children, while 400 children remained in Denmark.[77]

Decades later, the children at the centre of the story and the archives documenting that history have become resources for medical researchers. Epidemiologists have made use of records from the Finnish National Archives that document the evacuations to help study the effects of stress experienced in childhood on mental health later in life. It has been suggested that the stress of being separated from one's parents during childhood could be linked to "a higher risk of severe mental disorders" later in life.[78] To identify study participants who were evacuated during the Second World War, the researchers behind the Helsinki Birth Cohort Study made use of a register, created by the Ministry of Social Affairs and Health during the war, now held by the Finnish National Archives.[79]

The register, which has been described as a "highly reliable" source, provides information collected and compiled by the Ministry of Social Affairs and Health on the children evacuated between 1939 and 1946 by the Ministry of Social Affairs and Health.

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[77] Ibid., 449.
[78] Katri Räikkönen et al., "Risk of severe mental disorders in adults separated temporarily from their parents in childhood: The Helsinki birth cohort study," *Journal of Psychiatric* Research 45, no. 3 (March 2011): 333.
[79] Ibid.

This information aided researchers in identifying likely participants for the study.[80] Through this register, 1,719 adults who were separated from their parents as children were identified as study subjects. The hospital records of these individuals, such as discharge registers or death registers, were then examined by researchers who were looking for any diagnosis of psychiatric disorders "severe enough to warrant or contribute to hospital treatment" or "to be the underlying, intermediate or contributing cause of death."[81]

The conclusions drawn from this study were that adults who were separated from their parents in childhood had a higher likeliness of developing substance abuse and personality and mental disorders leading to a hospitalization or linked to their cause of death.[82] Furthermore, the register held by the Finnish National Archives has also been used to determine the links between childhood separation and depression. This latter study demonstrated that the children who were separated from their parents showed "20 percent more severe depressive symptoms than did those who did not experience any parental separation" during the war.[83] Those who had been separated from their parents for over three years presented an increased severity of these symptoms. The severity of symptoms also varied according to age, where children between the ages of four and six at the time of separation were less likely to suffer from depression.[84]

The evacuated children were also more likely to develop cardiovascular disease and type 2 diabetes later in life. This study, authored by Hanna Alastalo et al., explored the connection between childhood traumas and physical health in adulthood. They

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[80] Ibid.
[81] Ibid.
[82] Ibid., 336.
[83] Pesonen, et al., "Depressive Symptoms in Adults Separated from Their Parents as Children," 1131.
[84] Ibid.

stressed that children were subjected to traumatic experiences when they were initially separated from their birth parents and again when they returned to Finland and were separated from their foster parents. Long-lasting effects of the separation were evident, as adults who were separated from their parents as children "were twice as likely to have been diagnosed with cardiovascular disease and 1.4-fold more likely to have been diagnosed with type 2 diabetes."[85] Once more, researchers found that children separated from their parents for over three years were more likely to develop these illnesses.[86]

Researchers also found that reproductive traits and patterns were affected by the separation. Women who were evacuated as children "were 2.1 times [...] more likely" to start menstruating before they turned twelve years old.[87] This same study found that women who were separated from their families tended to have more children, having a 2.3 times greater chance of having at least four children. Men who had been evacuated as children tended to start having children at a younger age and there were shorter periods between the births of any subsequent children for these men than for men who had not been separated from their parents during the war. The study also concluded that evacuated children had greater chances of staying married to their spouses ("1.4-times more likely").[88]

The register that was created as a result of the evacuation of Finnish children during the Second World War has offered researchers a starting point in their study. They have been able to identify those who have been separated from their parents during the

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[85] Hanna Alastalo, et al., "Cardiovascular health of Finnish war evacuees 60 years later," *Annals of Medicine* 41, no. 1 (January 2009): 69.
[86] Ibid.
[87] Anu-Katriina Pesonen, et al., "Reproductive traits following a parent-child separation trauma during childhood: a natural experiment during World War II," *American Journal of Human Biology* 20, no. 3 (2008): 348.
[88] Ibid.

war due to these records, which list the names of the children sent to Sweden and Finland. The register serves as an enduring record of Finland's history throughout the war.

For researchers interested in the effects of trauma experienced during childhood on health later in life, the information provided in the Finnish register serves as evidence of an affected population. It proves that they can study questions surrounding childhood trauma because there are natural events that have been recorded and preserved, which provide them with circumstances under which they can seek answers to these questions. As Alastalo et al. say, they were able to launch their investigation of childhood trauma "mostly based on data extracted from the national archives."[89]

Though the insights gained from the Finnish register and the subsequent studies of the effects of childhood trauma on health have offered useful and compelling insights, they have only considered the effects of trauma on the individuals directly affected across the span of one lifetime. And yet, the effects of trauma can stretch much further than the lifetime of one individual. Certain traumatic experiences must be understood as intergenerational. These types of trauma are defined as a collective trauma that builds "both over the life span and across generations" among a given group or family.[90]

In Canada, the long history of forced assimilation and repression of First Nations at the hands of settler populations presents a case of historical and intergenerational trauma. From the late 1800s until the mid 1990s, the Canadian government, with the

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[89] Alastalo, et al., "Cardiovascular health of Finnish war evacuees," 71.
[90] Jessica R. Goodkind, et al., " 'We're Still in a struggle': Diné Resilience, Survival, Historical Trauma, and Healing," *Qualitative Health Research* 22, no. 8 (August 2012): 1021; Maria Yellow Horse Brave Heart, "The return to the sacred path: Healing the historical trauma and historical unresolved grief response among the lakota through a psychoeducational group intervention," *Smith College Studies in Social Work* 68, no. 3 (1998): 288.

support of certain churches, created and maintained residential schools where Aboriginal children, taken away from their parents and communities, were brought to be taught in an environment that denied them their language, tradition and culture. The effects of being separated from their families, being manipulated "to hate their Indianness" and, for many, being sexually and physically abused over the course of their time in the residential schools left many survivors traumatized while they attended the schools, after they left, and for the remainder of their lives.[91]

Scholars such as Ashley Quinn have argued that the encouragement, enhancement, and promotion of Indigenous cultures are important steps toward healing.[92] Another way to promote healing of historical traumas is by advocating for and supporting greater historical understanding. The history of Indian Residential Schools (IRS) in Canada remains to this day an obscure area of history for many Canadians, who are generally uninformed about the history of Aboriginal and settler relations in Canada. Unfortunately, many rely on the media for knowledge about residential schools, reducing a complex and lengthy history to "[s]hort sound bites about lawsuits, sexual abuse, and churches going bankrupt."[93] Moreover, many do not consider that the history of residential schools extends far beyond the opening of the first schools and the closing of the last. Such poor representation of IRS history in Canada fosters ignorance which, in turn, produces a hurdle for healing and reconciliation, as awareness and understanding

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[91] Paulette Regan, *Unsettling the Settler Within: Indian Residential Schools, Truth Telling, and Reconciliation in Canada* (Vancouver: UBC Press, 2010): 5; Theodore Fontaine, *Broken Circle: The Dark Legacy of Indian Residential Schools: A Memoir* (Canada: Heritage House Publishing Company Ltd.), 133.
[92] Ashley Quinn, "Reflections on Intergenerational Trauma: Healing as a Critical Intervention," *First peoples child & family review* 3, no. 4 (2007): 75.
[93] Legacy of Hope Foundation, "Where are the Children? Healing the Legacy of Residential Schools – Exhibit," Legacy of Hope Foundation, revised on June 26, 2009, accessed November 30, 2013, http://www.wherearethechildren.ca/en/exhibit/.

have been identified as key components of healing.[94] Moreover, healing from the trauma of IRS history will continue to be unattainable as long as trauma cannot "be expressed, validated and released in healthy, creative ways."[95]

To allow for validation and expression, the *Where are the Children?* exhibit has used archival records to promote healing in innovative ways. The exhibition presents the residential school experience through photographs, documenting the experiences of students from multiple generations. The exhibit has gathered and presented "118 framed archival photographs, text panels, maps, original classroom textbooks and historical government papers" collected from nine archival institutions including four church archives, as well as government archives such as Library and Archives Canada (then the National Archives of Canada) and the Archives of Manitoba.[96]

Text from the records of the Department of Indian Affairs were also integrated into the captions in the exhibit as the curator, Jeff Thomas, wanted to capture the language from the time in which the records on display were created.[97] These records were viewed through the exhibit in universities, galleries, museums, cultural centres and

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[94] Peter Harrison, "Dispelling Ignorance of Residential Schools," in *Response, Responsibility and Renewal: Canada's Truth and Reconciliation Journey,* eds. Gregory Younging, Jonathan Dewar, and Mike DeGagné (Ottawa: Aboriginal Healing Foundation, 2009), 171; Richard Kistabish, "Where are the Children? Healing the Legacy of Residential Schools – About Us" Legacy of Hope Foundation, revised on June 26, 2009, accessed November 30, 2013, http://www.wherearethechildren.ca/en/about/.

[95] Legacy of Hope Foundation, "Where are the Children? Healing the Legacy of Residential Schools – Exhibit: Intergenerational Impacts," Legacy of Hope Foundation, revised on June 26, 2009, accessed January 7, 2013, http://www.wherearethechildren.ca/en/exhibit/impacts.html.

[96] "Projects: WATC – Exhibition," Legacy of Hope Foundation, accessed on January 8, 2013, http://www.legacyofhope.ca/projects/where-are-the-children; Jeff Thomas, interview by Marilyn Maki, *CBC Radio Noon*, June 15, 2010, accessed on January 8, 2013, http://www.cbc.ca/player/News/Canada/Stolen+Children/Stolen+Children+Audio/ID/1522745822/.

[97] Jeff Thomas, interview, *CBC Radio Noon*.

various other venues across Canada. The exhibit is also currently available online and in the form of an app through iTunes.[98]

The exhibit aims to be thought-provoking and to encourage its audience to engage in dialogue through a question and answer discourse in hopes that this will further understanding and awareness of the greater context that surrounds IRS history and the issues that this history has provoked.[99] Without dialogue, healing historical traumas becomes more difficult. Breaking the silence becomes a crucial first step and the *Where are the Children?* exhibit has been recognized as a project that can fuel dialogue and be conducive to healing "by moving those who need to speak to speaking, and those who need to listen to listening."[100]

Where are the Children? presents an unconventional approach to healing, one that strays away from western practices. However, when dealing with intergenerational trauma, these "Western/European interventions of mental health have been identified as generally ineffective" among Indigenous people.[101] Creative projects such as the *Where are the Children?* exhibit contribute to legacy education that "seeks to raise awareness of the residential school (or other traumatic experiences and consequences)" and promotes

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[98] "Where are the Children? Healing the Legacy of the Residential Schools," Legacy of Hope Foundation, revised on June 26, 2009, accessed November 30, 2013, http://www.wherearethechildren.ca; Tristan Interactive Inc., "Legacy of Hope: Where are the Children?" iTunes Store, version 1.0 (2012), https://itunes.apple.com/ca/app/legacy-hope-where-are-children/id546418837 (accessed on November 30, 2013).

[99] "Where are the Children? Healing the Legacy of Residential Schools – Exhibit," Legacy of Hope Foundation, revised on June 26, 2009, accessed November 30, 2013, http://www.wherearethechildren.ca/exhibit/.

[100] George Erasmus, " 'Where are the Children?' – an exhibition launch," presented at the Legislative Assembly of the Northwest Territories, Yellowknife, Northwest Territories, September 27, 2003.

[101] Quinn, "Reflections on intergenerational trauma," 75.

understanding among families affected by IRS history "which in turn can motivate survivors and youth to pursue healing."[102]

As such, the exhibit becomes a "catalyst for healing" by providing survivors and their descendants with means to initiate dialogue.[103] The exhibit also depicts stories of survivors that promote a "sense of strength and endurance" that viewers may be "looking at today and relying on for healing."[104] These photographs, which were originally created by churches and the federal and provincial governments for their own administrative and other purposes, have created opportunities for discussion and healing.

Archival records are most versatile when users find ways of using these records in new and innovative ways that were never considered by others. A record created for one purpose might be used by someone else for entirely different aims. The records presented in the *Where are the Children?* exhibit were created by governments and churches that were documenting their attempted assimilation of Aboriginal communities into the Euro-Canadian, Christian culture.

Decades later, Jeff Thomas has found that these records could be used to promote healing and empowerment among Aboriginal people and raise awareness of the troubled history of the relationship between Aboriginal and non-Aboriginal Canadians. The documents are the same, the people, buildings, and settings depicted in the photographs are no different from when they were first taken. However, the context has changed. The records have been re-contextualized in this exhibit. In this setting, the photographs are

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[102] Urban Society for Aboriginal Youth, YMCA Calgary, and University of Calgary, "Intervention to Address Intergenerational Trauma: Overcoming, Resisting and Preventing Structural Violence," *Intergenerational Trauma and Aboriginal Youth* (Winter 2013): 9.
[103] Kishk Anaquot Health Research, *Third Interim Evaluation Report of Aboriginal Healing Foundation Program Activity* (Ottawa: Aboriginal Healing Foundation, June 2003), xiv; Tristan Interactive Inc., "Legacy of Hope: Where are the Children?"
[104] Tristan Interactive Inc., "Legacy of Hope: Where are the Children?"

given a new meaning and they encourage new interpretation. Voices of the silenced can be addressed and heard. Records that were once tools of oppression can be transformed into aids to healing, reconciliation and learning. Archives play a role in this process – a role that was never intended or envisioned by the original creators documenting the IRS experience.

In fact, the research projects discussed in this chapter have all made use of archival records in ways that were never considered when the records were initially created. They have formulated new questions and found new meanings in old records. They have looked beyond the administrative purposes of military records, pension files and censuses and seen that these records can reveal valuable medical information about historical exposure to traumatic events and foster opportunities to learn more about trauma so that it may be better treated. They have looked at data collected to examine the development of gifted children and recognized that the information was collected at a unique moment in time and, as a result, offered a perspective that could yield promising insights into the effects of combat. A register created in Finland during the Second World War became the source of information about a cohort of children affected by trauma. Government documents became art, exhibited to inspire discussion, empowerment and collective healing.

This chapter has mentioned Verne Harris's notion that archivists should not simply be "servers of records users" but "*creators* of users."[105] Many of the examples explored in this chapter have demonstrated that users can in fact share in this role. The Union Army data project has served as a prime example of the strong impact that archival use can have on indirect use, allowing users to promote use and create users. Based on

[105] Harris, "Redefining Archives in South Africa," 18.

the initial data collection of Civil War records, many publications have indirectly used archival records from NARA.

The knowledge obtained from data archives such as the Terman data archive has been so useful to scholars such as Elder, Shanahan and Clipp that it has led to the publication of a book on how to use data archives for research purposes.[106] While archivists can make use of this publication to gain a better understanding of data archives users, the book was primarily published to encourage and assist other researchers using data archives.

Similarly, the scholars behind the collection of the Union Army data have also written a chapter on how they began the project and collected the data.[107] Once again, this publication can present archivists with an opportunity to learn more about new user groups and provide users with a guide on how to begin similar projects. These projects allow archival materials to be accessible online, reaching a greater audience. The *Where are the Children?* exhibit has also encouraged indirect use of archives by making available resources that promote discussion and healing online and integrating the archival materials used in the exhibit to do so. Archivists who strive to encourage and facilitate greater access but struggle to find the resources to do so can consequently look to those responsible for projects such as *Where are the Children?* and the Union Army data as allies.

But while granting access to records generated by trauma can encourage further use and greater archival visibility, stewarding records of trauma comes with added considerations for archivists. Core considerations in stewarding records of trauma should

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[106] Elder, Pavalko, and Clipp, *Working with Archival Data.*
[107] Wimmer, "Reflections on the Early Indicators Project."

not differ from the considerations applied to other records. However, those considerations – ethical and legal implications, appropriate use, establishing trust and being accountable to stakeholders – acquire new layers of meaning and consequence with records of trauma.

Some records, like those generated by traumatic events and histories can attract greater attention and might have "high, enduring public accountability and enduring value" – meaning that access and accountability carry greater significance not only in a single moment but in the long-term.[108] This Greater attention, however, may not only be focused on the uses of archival records, but also on the failures of the institutions managing them. For records related to the residential schools, for example, many were destroyed over the course of the nineteenth and twentieth centuries.[109] The absence of these records has made the process of holding the government accountable for its actions more difficult and leaves users with a void in the records they seek to access.

Whether archivists have inherited the records void or created it, it is important that they document their understanding of that history or provenance of the records and whatever role they have played in that history so that they themselves may be held accountable. The mediations and interventions of archivists are not always made evident by archival institutions. But when these actions have repercussions on a public that seeks records for purposes of accountability, archivists must go beyond being "keepers" of records and acknowledge their role as "shapers of the past."[110]

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[108] Laura Millar, "Coming Up with Plan B: Considering the Future of Canadian Archives," *Archivaria* 77 (2014): 120, 125.
[109] Gwen Reimer et al., *The Indian Residential Schools Settlement Agreement's Common Experience Payment and Healing* (Ottawa: Aboriginal Healing Foundation, 2010), 29.
[110] Elizabeth Snowden Johnson, "Our Archives, Our Selves: Documentation Strategy and the Re-Appraisal of Professional Identity," *The American Archivist* 71, no. 1/2 (Spring/Summer 2008): 193.

Many users, including medical researchers, turn to archival records to find reliable documentary evidence. And while definitions of reliability might vary from one user or user group to another, overall, the credibility of archival documents cannot be ensured if the archival institution itself is not accountable for its practices.[111] Projects explored throughout this chapter have made archival records more accessible to the public because they have recognized the value of the records they used in unveiling new information about trauma and how it is related to physical and mental health, and how it can be dealt with in healthy and creative ways. They have relied on the existence and preservation of records that document the experiences of individuals in traumatic circumstances.

These circumstances were shaped both by the period and the environments in which the records utilized were created, whether the subjects documented in the records lived through times of oppression, financial hardship, or at a time where medical knowledge had yet to catch up with their illnesses. They may have faced unfamiliar environments when sent to war, or when displaced, be it to a residential school or to a new country.

These examples show how archival records have enabled investigations of the relationship between trauma, health, and healing. Traumatic experiences have a significant impact on the health of the individuals affected, and on the people around them and even future generations. But the study of trauma relies heavily on the past. Researchers cannot create a traumatic environment to study its consequences and so, the evidence which remains after trauma has occurred becomes crucial to researchers. And as

[111] Terry Cook, " 'A Monumental Blunder': The Destruction of Records on Nazi War Criminals in Canada," in *Archives and the Public Good: Accountability and Records in Modern Society*, eds. Richard J. Cox, and David A. Wallace (Westport, CT: Quorum Books, 2002), 64.

human memory can be altered, or become less reliable over time, researchers have sought out documented evidence of these memories and found answers in old records, and the archives which house them.

Chapter Three: Social Environments, Health and the Search for Relevant Records

Beyond documenting the lives of individuals from birth to death, archival records have also recorded the social environments surrounding them. The role of environment as a player in the health of individuals can be examined through archival sources that detail the settings in which individuals exist – where they work, where they live, where they travel. Retrospectively, such sources can help assess if, and to what degree, these environments have had an effect on health. In this regard, archival records have contributed to studies that have triggered larger health-related discussions on an international scale.

These discussions have influenced city planning, dialogue on vaccination strategies, and the treatment and prevention of large-scale epidemics. The records that have engendered these actions include convent records from the Netherlands, population registries from Sweden, and military records from New Zealand. These records were created over the span of the twentieth century, starting with the First World War. Yet, even though many conclusions about the role of environment in health have been drawn from archival records, obstacles to health-related knowledge have also been encountered when such sources were not properly preserved. Consequently, the importance of such archival records has been noted both through the presence of accessible sources and their absence.

As long as they are properly preserved, archival records hold evidence of the many environments that document the lives of people and their surroundings. The living environment was of particular interest to researchers in Sweden. Working in the field of epidemiology at the Karolinska Institute in Sweden, Maria Feychting and Anders

Ahlbom have studied the link between places of residence and health. Their study proposed that extended proximity to high-voltage power lines could be linked to a higher risk of developing cancer. The study focused on 500,000 people in Sweden, including both children and adults who, between 1960 and 1985, resided no more than 300 meters away from power lines that emitted between 220 and 400 kiloVolts. The study made use of a population registry held by the Stockholm City Archive to determine who lived in areas near power lines. They also made use of the Swedish Cancer Registry to identify people who had been diagnosed with cancer in the geographical areas of interest to their study.[1]

The study concluded that while there was no significant link between central nervous system tumors or lymphoma and proximity to power lines, a valuable finding in itself, there was an increased risk among children and adults of developing leukemia if they were exposed to magnetic levels of 0.2 microtesla or higher.[2] In fact, children living in these areas were approximately 3.8 times more likely to develop leukemia.[3] Adults, on the other hand, were 1.7 times more likely to develop leukemia if they lived near power lines.[4]

The Swedish study provoked a shift in viewpoints on electromagnetic fields from one "which most of the research world regarded as nonsense in the early '70s" to one that was considered to be "a high-priority research area" two decades later.[5] While Feychting and Ahlbom's study received great attention, it was not the first to examine the link

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[1] Maria Feychting, and Anders Ahlbom, "Magnetic Fields and Cancer in Children Residing Near Swedish High-voltage Power Lines," *American Journal of Epidemiology* 138, no. 7 (October 1, 1993): 467.
[2] Ibid.
[3] Ibid., 476.
[4] Maria Feychting and Anders Ahlbom, "Magnetic Fields, Leukemia, and Central Nervous System Tumors in Swedish Adults Residing near High-Voltage Power Lines," *Epidemiology* 5, no. 5 (September 1994): 504.
[5] Maryalice Yakutchik, "A new jolt of concern," *Lawrence Journal - World,* January 2, 1993, 6.

between power lines and leukemia. In 1979, one study examined the link between 344 children who died of leukemia in Denver and their living proximity to power lines. In 1988, another Denver-based study further argued that power lines were linked to childhood cancers.[6] The first study was disregarded by the general scientific community while the second was downplayed as being unique to the population of Denver.[7]

The 1992 study garnered greater attention in part because of its archival sources. The preservation of "historical registries of residences" has been described as "invaluable" as it assisted Feychting and Ahlbom in creating "exposure histories" of their subjects.[8] Their findings were unprecedented based on the precision of their data on electromagnetic field exposure measures.[9] Furthermore, the results of the study had a great effect on the public. Besides being cited by over 750 scholarly sources in the years following its publication, the study also received attention in the popular press, with newspaper articles asserting that the study provided "the best evidence" of a connection between power lines and cancer. [10]

The article also triggered responses from readers of news sources. One letter to the editor responding to the electrification of an Amtrak rail in Boston asked "Do the Amtrak people know about the Swedish study?" Likewise, still on the subject of the

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[6] Nancy Wertheimer and E. Leeper, "Electrical Wiring Configurations and Childhood Cancer," *American Journal of Epidemiology* 109, no. 3 (1979): 273-284; David A. Savitz et al., "Case-control Study of Childhood Cancer and Exposure to 60-Hz Magnetic Fields," *American Journal of Epidemiology*, 128, no. 1 (1988): 21-38.

[7] Yakutchik, "A new jolt of concern," 6.

[8] Paul Elliott and Daniel Wartenberg, "Spatial Epidemiology: Current Approaches and Future Challenges," *Environmental Health Perspectives* 112, no. 9 (June 2004): 1003.

[9] Richard Stone, "Polarized Debate: EMFs and Cancer," *Science* 258, no. 5089 (December 1992): 1724.

[10] Citation count based on the "cited by" count from Google Scholar as of July 5, 2015 for the following publications: Feychting, and Ahlbom, "Magnetic Fields and Cancer in Children," 467-481; Feychting, and Ahlbom, "Magnetic fields, leukemia, and central nervous system tumors in Swedish Adults," 501-509. For examples of press coverage related to the Swedish Study, see: "Health Notes: Study links power lines, Leukemia," *Sarasota Herald-Tribune,* November 12, 1992, 10A; "Power Line Study: Study: Proximity to wires can up risk of leukemia," *The Telegraph*, November 12, 1992, 8; Mary McAleer Vizard, "Measuring the Threat of Power Lines," *The New York Times*, July 18, 1993.

Amtrak rail in Boston, Elizabeth M. Rajec asked fellow readers of *The New York Times*, "Could we not learn from Sweden and guard our children from such 'possible' health risks?"[11] The study further led to discussions among national organizations and governments. The Swedish government held discussions on controlling electromagnetic exposure by setting "a national standard of two milligauss as a safe level of exposure."[12]

Sweden's National Board for Industrial and Technical Development would not confirm that there was a definite link but it did declare that the study results warranted further investigation into the connection between health and electromagnetic fields. In fact, the National Board would "act on the assumption that there [was] a connection between exposure to power frequency magnetic fields and cancer," a declaration that was unprecedented on an international scale as no government had ever acknowledged the connection.[13]

Following this statement, the Vattenfall power company in Sweden worked with the National Board to develop guidelines related to new power line installations and the construction of new homes and childcare establishments near current power lines.[14] Other institutions, such as the Swedish National Institute of Radiation Protection, adopted a similar stance. Overall, Swedish officials agreed that they should "take a cautious standpoint and [...] support further studies on the matter."[15]

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[11] Pamela M. Cannon, "To the Editor: Electrification is a health hazard," *The Day*, April 23, 1993, A10; Elizabeth M. Rajec, "To the Editor: Electric Fields," *The New York Times*, January 10, 1994.
[12] Mary McAleer Vizard, "Power lines Raise Fears in Home Buyers" *The New York Times,* July 11, 1993.
[13] Thomas H. Maugh II, "Studies Link Electromagnetic Fields, Cancer," *The Los Angeles Times*, November 9, 1992, accessed January 13, 2015, http://articles.mcall.com/1992-11-09/news/2887823_1_emf-studies-link-electromagnetic-fields-childhood-cancer.
[14] Stig Goethe, "EMFs and Health Risks: Research and Reactions in Sweden," *IEEE Power Engineering Review* 13, no. 10 (October 1993): 17-18.
[15] Ibid., 18.

A few weeks after the study was published, the United States Congress conducted a $65,000,000 investigation to examine the connection further.[16] While American epidemiologists such as David A. Savitz, Nancy Wertheimer, and Ed Leeper had published studies on the topic of magnetic fields and cancer before the publication of Feychting and Ahlbom's findings, *The Los Angeles Times* argued that these studies lacked proper documentation of exposure levels.[17] Feychting and Ahlbom's use of population registries made their study more credible, leading the United States to take more concrete measures to investigate the connection further. In the fall of 1992, the Department of Energy also sponsored a conference for Electromagnetic Field researchers in San Diego where Feychting and Ahlbom were invited to speak and present their findings.[18] Their work was of primary interest during the conference.

The link between cancer and electromagnetic field exposure is still debated today, but it is undeniable that the work of Feychting and Ahlbom sparked an international discussion of the topic. And while archival sources have played a strong part in their research, the term 'archive' is seldom used in the sources cited above. Even in their study of leukemia in children, Feychting and Ahlbom not only make minimal reference to archives but describe their experience with the archives unfavourably. A single reference to the Stockholm City Archives calls the process of collecting data "extremely time consuming" as

> space in the archives where the Stockholm data were stored and the way in which the material was organized prohibited the simultaneous

[16] Vizard, "Power lines Raise Fears in Home Buyers."
[17] Wertheimer and Leeper, "Electrical Wiring Configurations and Childhood Cancer," 273-284; Savitz et al., "Case-control Study of Childhood Cancer," 21-38; Thomas H. Maugh II, "Studies Stir Fears Over Cancer Risk for Children Research," *The Los Angeles Times,* November 8, 1992.
[18] Maugh, "Studies Link Electromagnetic Fields, Cancer."

> employment of more than two or three people for this task. Thus, the work could not be speeded up by the enrollment of more personnel.[19]

While brief, this reference offers two criticisms directed at the archival institution. The first is directed at the organization of the materials. As they do not elaborate on how the material was organized, it is difficult to examine where the problem lies. They may be referring to arrangement. In this case, it is also difficult to determine whether the arrangement of the material would be problematic for other users or only for those who are using the registry for similar purposes as Feychting and Ahlbom.

Arrangement is most often determined by creator or archivist, or a combination of both.[20] While archivists often consider how to make their resources discoverable and accessible for their users, arrangement is often already determined before they or researchers examine the records. Arrangement is based on the records' provenance, as groups of records from a common creator and usually generated from a common function are maintained in what is often called a *fonds* or a "series" respectively, rather than according to their subject matter content.

Arranging records in this way places the emphasis on protecting the value of the records as evidence of the actions that created them. This serves all researchers by enabling them to understand the records in this key context. A subject content rearrangement would at best support only certain researchers and at worst undermine all research by eroding knowledge of that key initial context. However, when faced with varying uses of a group of records, it is important to consider how this arrangement

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[19] Feychting, and Ahlbom, "Magnetic Fields and Cancer in Children," 469.

[20] Exceptions to this are present in articles such as Katie Shilton, and Ramesh Srinivasan, "Participatory Appraisal and Arrangement for Multicultural Archival Collections," *Archivaria* 63 (2007): 87-101, which looks at involving the community represented by the archives in archival practices such as appraisal, arrangement and description.

benefits or hinders the researcher. In online databases, keyword access points to finding aids can facilitate subject-based access to a provenance-based arrangement of records. Such flexible approaches by archivists are needed to support as wide a variety of researchers as possible.[21]

Feychting and Ahlbom's critique might also be referring to the organization of materials that facilitate intellectual control of records, such as finding aids. A potential issue with finding aid organization might be that the descriptions provided were too high-level. Researchers were only interested in individuals residing near power lines. Perhaps the finding aid structure did not allow them to clearly locate files relevant to their research, and consequently they may have had to go through many irrelevant registries before finding those of use to them.

In cases where collections of records accommodate a significant volume of smaller components such as files or items, many archives will only process and describe at the higher-levels of the overall *fonds* or series as it is more efficient in terms of resources, supporting the notion that "good processing is done with a shovel, not with tweezers."[22] However, many users are interested in the files or items and, if the collection of records includes a high volume of them, a higher-level description may provide less meaningful information as it describes more vaguely a large quantity of records and may make the process of retrieving and using archival records more difficult for new users or user groups. Consequently, a vague or poorly organized finding aid can make the process of retrieving relevant materials more difficult and hinder use.

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[21] Isto Huvila, "Participatory Archive: Towards Decentralised Curation, Radical User Orientation, and Broader Contextualisation of Records Management" *Archival Science* 8, no. 1 (March 2008): 16.

[22] Mark Greene and Dennis Meissner, "More Product, less process: Revamping traditional archival processing," *The American Archivist* 68, no. 2 (2005): 240.

Furthermore, archivists have certain obligations to their users that in this case, may not have been met. Archives are meant to be used but for that to go on in the long-term, records need to be preserved. While these two aims should be congruent, archival institutions often come across as being "materials-centered" rather than "client-centered."[23] To be client, or user-centered, archives need to consider the research patterns and needs of their clients. This includes considering research time constraints as all users may not have the "commitment nor the time or training to burrow for" information and this may dissuade them from using archives "not because [the] material is irrelevant […] but because of the difficulty users have in reaching the information hidden in the records."[24]

With the new and more varied uses of archives, such as in the health and scientific fields, especially, archivists can no longer work under the assumption that users come to the archives knowing exactly what records they need and how to interpret and use the materials they are consulting. For those new users who are only beginning to turn to archival institutions, negative experiences may dissuade them from returning.

A second critique of the Stockholm City Archives by Feychting and Ahlbom refers to archival user space. While researchers identified twenty-one power lines which might affect children residing in the vicinity, they could only collect data related to nineteen of those power lines due to time constraints and the fact that only three people could work on data collection at once due to the research space provided by the

[23] Elsie T. Freeman, "In the Eye of the Beholder: Archives Administration from the User's Point of View" *The American Archivist* 47, no. 2 (Spring 1984): 112.
[24] Ibid.

archives.[25] Subsequently, they attributed their inability to collect data from all the power lines in Stockholm to their work environment: the city archives in Stockholm.[26]

Important to consider, and in line with the theme of this chapter, are issues around environment. However, here the term refers to the environment that an archive provides to its users, its "reference environment." [27] Ideally, an archive should provide spaces for users that are conducive to their research needs. Of course, many archives are limited in terms of financial resources and space, and struggle to strike a spatial balance between user needs and storage needs.[28] Beyond this, different users have different spatial needs. Some users may find that a quiet space where they can work alone is more suited to their research activities, while others may need to work in groups. The latter was the case for the research done by Feychting and Ahlbom but unfortunately the Stockholm City Archives did not provide a workspace for more than three people, limiting the size of the research group.

In his time as the Director of the National Archives of Australia's Darwin office, Ted Ling evaluated the design of archival repositories in Australia and addressed the importance of considering all users when designing a reading room. Doing so would require an archive to take into consideration the various activities that could take place in a reading room. To achieve this, Ling argued, an archival institution would need "multiple reading rooms [...] or a single room which allows all [...] functions to

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[25] Feychting, and Ahlbom, "Magnetic Fields and Cancer in Children," 469.
[26] Ibid.
[27] Laura A. Millar, *Archives: Principles and Practices* (New York: Neal-Schuman Publishers, Inc., 2010), 187.
[28] Kacy L. Guill, "Arguing for Space in an User-Focused Environment," *Library & Archival Security* 22, no. 2 (July 2009): 188.

coexist."[29] Such functions included the use of microfilm, computers, the need for group discussion during research, and the use of certain record types that demand certain spaces. The latter could include larger tables for researchers using maps, blueprints or other records that tend to occupy more space, or quiet areas for researchers using audiovisual materials. Quiet areas may also be beneficial to users relying on devices such as tape recorders.[30]

Encouraging and maximizing archival use "should be a centerpiece of the archival mission."[31] Consequently, the space that accommodates this use should be conducive to the research activities of its users. The space used by Feychting and Ahlbom was not conducive to their work. By Ling's standard, group work areas in an archive should be large enough to allow four or five people to work at once.[32] Such a space would have allowed for twice as many data collectors in the power line study. Many archivists would like to be able to offer such ideal accommodations to their users. And yet, for many institutions, this is an ideal that is very difficult to reach when faced with limited staff and research space.

If archivists seek to promote use among those who require group spaces, along with prolonged access to records to complete their research, then they must think outside the box. More specifically, archivists may consider thinking outside the archive, moving beyond what Steven Maynard calls "archival panopticism" where user spaces are designed in such a way to ensure that users are under the surveillance of archivists.[33]

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[29] Ted Ling, *Solid, Safe, Secure: Building Archives Repositories in Australia* (Canberra: National Archives of Australia, 1998), 77.
[30] Ibid.
[31] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 86.
[32] Ling, *Solid, Safe, Secure*, 77.
[33] Steven Maynard, "Police/Archives," *Archivaria* 68 (Fall 2009): 177.

Whether records are kept under the control of archivists to ensure their long-term preservation, their chain of custody, or their safety, these efforts may be counterproductive to use. In terms of outreach, archival records are most visible to the public outside the walls of the archives. They are visible when they are referenced in an article, in a book, or online exhibits, or in other media sources. Yet, they are visible as representations, references of their physical counterparts, which remain in the archive. If these records were taken outside of their archival environment, could outreach be improved? Could archival visibility become greater? Could use be increased?

With respect to use, allowing researchers to access the records they need outside the walls of an archival institution may provide them with more flexibility to complete their research in spaces that are appropriate for their needs and promote further and more effective use of records.[34] Despite traditional archival practices, taking the records out of the archive is not unprecedented. The Wisconsin Historical Society has coordinated the loaning of archival materials to other institutions in the area for nearly 50 years.[35] The Regional Historical Resource Depositories in Texas and the Joint Collection of Missouri Western Historical Manuscript Collection & State Historical Society of Missouri Manuscripts have also organized loaning networks.[36] Many archives will also loan their materials to other cultural institutions, such as museums, so that these institutions can integrate archival materials into displays.

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[34] Timothy L. Ericson, and Joshua P. Ranger, " 'The Next Great Idea': Loaning Archival Collections," *Archivaria* 46 (Spring 1999): 103.
[35] Ibid., 86; Wisconsin Historical Society, "Area Research Center Network," accessed April 14, 2014, http://www.wisconsinhistory.org/libraryarchives/arcnet/.
[36] Timothy Ericson, "Survey of Archival Networks," *The Midwestern Archivist* 6, no. 2 (1982): 114, 106; Texas State Library and Archives Commission, "About the Regional Historical Resource Depository (RHRD) System," updated February 14, 2014, accessed May 19, 2014, https://www.tsl.texas.gov/shc/countyrecs/index.html; The State Historical Society of Missouri, "The State Historical Society of Missouri," updated May 19, 2014, accessed May 19, 2014, http://shs.umsystem.edu/index.shtml.

Loaning archival records to study health issues is also not unprecedented. The records used to develop the fetal origins hypothesis examined in the first chapter of this thesis were loaned to Southampton University on a long-term basis. Furthermore, as long as these records are in their custody, Southampton University controls access to the records on behalf of the Hertfordshire archives.[37] Snowdon's Nun Study had enough funding to maintain its own archives room within the Nun Study offices, equipped with "compact shelving for storage of documents and audiovisual materials, and [...] a separate thermostat for temperature control." Records were stored in "archival boxes" and a database was created to facilitate records retrieval. Users of the database could search by number, name or media type. [38]

In cases like these, users who are conducting research through well-established institutions, such as universities, may have access to those resources that archives may lack – including research space that is favourable to their specific needs. Feychting and Ahlbom both worked at Karolinska Institute, a medical university that is responsible for over "40% of all academic medical research in Sweden."[39] As such, they may have had access to better-suited research spaces and, if their research funding could provide for proper care of the records, agreements similar to those made between Barker and the Hertfordshire archives or Snowdon and the SSND archives could have been made.

Although the preservation of records is important to consider in agreements such as these, and can be adequately addressed, another concern is that other researchers (who are not affiliated with the borrowing institution) have equal access to the records while they are outside an archive's custody. As long as proper arrangements are made for

[37] Hertfordshire Archives and Local Studies email to Natalie Vielfaure, September 25, 2013.
[38] Patzwald, and Wildt, "The Use of Convent Archival Records in Medical Research," 93.
[39] Karolinska Institutet, "About Us", accessed June 20, 2014, http://ki.se/en/about/startpage.

transfer, care, handling, and accessibility while the records are in the custody of another institution, the overall preservation of those records should not be threatened to any significant degree.

Minimizing barriers to access and use could have brought more positive attention to archival research as Feychting and Ahlbom's study garnered international attention and influenced public discussion, national policies on electromagnetic standards, and further research into electromagnetic exposure and its connection to cancer. It was, in fact, the sources utilized by Feychting and Ahlbom that allowed their study to be better received than similar previous studies. Had documentation on the residential environments of study participants been unavailable, the study would not have reached the same findings or had as great an impact.

Just as archives that document residential environments have prompted larger discussions, so have records that document isolated environments. Such records have contributed to the study of pertussis and a greater conversation about the effectiveness of vaccines. In 1992, a group of nuns, Servants of the Holy Ghost, residing in a convent in the Netherlands, were faced with an outbreak of pertussis. The incident came to the attention of Paul Mertens, Gerard Borsboom, and Jan Hendrik Richardus, researchers in the field of public health in Rotterdam. None of the seventy-five sisters living in the convent had been immunized against pertussis while all but three employees out of the twenty-four who worked in the convent but lived elsewhere had been immunized. Among the seventy-five sisters, sixty-six were "career nuns," meaning that they worked beyond the walls of the convent – in schools, hospitals or abroad on missions – in the years that

followed their profession of vows. The remaining nine nuns had "convent career[s]" as they only occasionally left the convent and seldom welcomed guests.[40]

When the outbreak occurred, forty-five nuns developed pertussis while only two employees were affected. The latter were among the vaccinated population of the study. Furthermore, the nine "convent career" nuns all contracted pertussis, meaning that one hundred percent of these nuns were affected. Only fifty-five percent of the "career nuns" contracted pertussis.[41] The more exposure that nuns faced outside the convent, the less susceptible they were to contracting pertussis during the outbreak. In fact, sisters who worked outside the convent in the Netherlands but also abroad on missions were less likely to develop pertussis than nuns who had only worked in one of these two environments during their time outside the convent:

> The pertussis incidence among nuns who had worked in Dutch society only (n = 38) was 74%; in those who had worked in the tropics only (n = 22), it was 35%; and in those who had worked in both the Dutch society and the tropics (n = 6), it was 17%.[42]

Thus, the results of the study demonstrated that living in a more isolated and less diversified environment increased a person's susceptibility to pertussis. While isolation might protect an individual from contracting pertussis in the first place, the study concluded that once the Bordetella pertussis bacteria was introduced into an isolated environment, it could spread more easily among the population.[43]

The study made use of the convent's "well-kept archive" to determine the level of isolation that sisters had faced in the years prior to the epidemic, as files could be

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[40] Paul L. J. M. Mertens, Gerard J. J. M. Borsboom, and Jan Hendrik Richardus, "A Pertussis Outbreak Associated with Social Isolation among Elderly Nuns in a Convent," *Clinical Infectious Diseases* 44, no. 2 (January 2007): 266-67.
[41] Ibid., 267.
[42] Ibid.
[43] Ibid., 268.

obtained from the archive that detailed their careers, both inside and outside the convent.[44] Archival sources from the convent were also used to look into the convent's history of epidemics. As there was no mention of an epidemic prior to the 1992 outbreak in the convent's archive, living in an isolated environment seemed to have protected the sisters from other epidemics prior to the pertussis epidemic.

However, in 1992, when the mean age of the nun population was seventy-five years, the convent accommodated a more diverse population as it "changed from a closed congregation into an open nursing facility for elderly nuns aided by civil staff."[45] This increase in population, more specifically, the introduction of individuals who had lived, worked and socialized among more diversified environments throughout their lives into an environment that was occupied by more isolated residents prior to 1992 led to the outbreak. The nuns had most likely never been exposed to pertussis during their time in the convent and so, when the virus was introduced into the convent, and as they had never been vaccinated against it, they had no built-up immunity against pertussis.

The study has contributed to a larger dialogue on vaccination strategies as it made mention of the waning effectiveness of both vaccinations and natural immunity against pertussis. While none of the sisters were immunized against pertussis as children, they may very well have been exposed to it at some point before they entered the convent. However, the authors point out that immunity to pertussis brought on by early life exposure or by vaccination will only last for a limited time as "infection-acquired immunity wanes after 4-20 years and [...] vaccine-acquired immunity wanes after 4-12

[44] Ibid., 266.
[45] Ibid.

years."[46] This would also explain why previously vaccinated staff members contracted pertussis. For this reason, the authors close their examination of pertussis among elderly nuns by suggesting that people should not only be vaccinated against pertussis but also receive booster shots at different points in life to prevent repeat epidemics, a notion supported by many articles, some of which have cited the work of Mertens, Borsboom, and Richardus in their own research.[47]

While many convent archives document the careers of their nuns, Mertens, Borsboom, and Richardus recognized that these records also documented the environment in which these careers took place. The value of convent and religious archives to many varied subjects unrelated to religious topics has been recognized by many user groups. These groups were interested in research subjects such as musicology, genealogy, demography, and secular histories including economic history, women's history and social history.[48]

In the study of health, religious communities offer study populations sharing a consistent lifestyle, which allows researchers to identify patterns and link them to health events. For communities such as the Servants of the Holy Ghost, detailed records of these patterns also facilitate the work of researchers by documenting those patterns. As observed by Dr. Snowdon in the course of his work studying the School Sisters of Notre Dame, nuns share many of the same traits as "[t]hey do not smoke. They are celibate.

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[46] Ibid., 268.

[47] Ibid. See for example: Iman Ridda, et al., "The importance of pertussis in older adults: A growing case for reviewing vaccination strategy in the elderly," *Vaccine* 30, no. 48 (November 2012): 6745-6752; Steven J. Scheweon, "Pertussis: Not just for kids anymore," *Nursing* 41, no. 10 (October 2011): 61-62; D. Piérard, et al., "Transmission de Bordetella pertussis dans les hôpitaux : un réel problème ?" *NOSO-info* XI, no. 2 (2007): 13-16.

[48] David A. Haury, "The Research Potential of Religious Archives: The Mennonite Experience," *The Midwestern Archivist* 11, no. 2 (January 1, 1986): 135, 139; Robert C. Ray, "No one has Ever Seen God: The Use of Religious Archives for Nonreligious Purposes," *Journal of Religious & Theological Information* 7, no. 3-4 (2009): 151.

They have similar jobs and income, and they receive similar health care for most of their lives."[49] The presence of these commonalities minimizes variables that exist among more diversified populations. More varied lifestyles – different routines and occupations, for example – can obscure a clear connection.

For instance, based on the hypothesis that low birth weight is linked to cardiac problems, a subject who was underweight at birth and later died of a heart attack in middle age could support this theory. However, if this individual was a heavy smoker, this habit could discount the theory as it could be argued that while the heart attack could have been predicted based on their birth weight, smoking could also be a culprit. As a result, it becomes more difficult to state that there is a clear connection between birth weight and heart health, based on numerous variables. In religious communities, these variables are reduced based on more similar and structured lifestyles. In some cases, these communities have day-to-day routines that help researchers establish patterns, including daily schedules with precise hours designated for meals, work, prayers and sleep.[50]

Just as the nuns studied by Snowdon, "with their carefully regulated lives and copious records, [were] ideal subjects", so were the Servants of the Holy Ghost for Mertens, Borsboom, and Richardus.[51] The ability to conceptualize the circumstances and environment in which health epidemics emerge can provide key evidence of the underlying causes of a given illness or the reasons why it was transmitted to such a high degree as to cause an epidemic. Beyond the Dutch nun study, others have used archival

[49] Snowdon, *Aging with Grace*, 14.
[50] E. Perry McCullagh, and Lena A. Lewis, "A study of diet, blood lipids and vascular disease in Trappist monks," *New England Journal of Medicine* 263, no. 12 (1960): 569.
[51] Snowdon, *Aging with Grace*, 2.

sources to gain insight into the environmental factors that caused the 1918 Spanish Influenza pandemic. As the epidemic erupted in the context of the First World War, the circumstances under which people contracted the virus are well documented. Furthermore, the war environment may have had a significant impact on the pandemic.

Other influenza outbreaks, such as those in 1889, 1957 and 1968 caused lower death tolls, with one to two million people succumbing to influenza in each of these epidemics.[52] Keeping this in mind, those studying the Spanish Influenza pandemic have suggested that a global conflict, the First World War, produced the circumstances which contributed to the much higher loss of forty million lives in 1918-1919.[53] This claim is based on the notion that the propagation of Spanish Influenza "depended on the transportation of large numbers of troops during World War I."[54]

It has been argued that the Spanish Influenza outbreak of 1918 was strongly linked to the war. The circumstances under which soldiers served allowed the disease to spread. These included:

> the mixing on French soil of soldiers and workers from the five continents, the very poor quality of life of the soldiers, agglomeration, stress, fear, war gasses used for the first time in history in a massive and indiscriminate manner, life exposed to the elements, cold weather, humidity and contact with birds, pigs, and other animals, both wild and domestic.[55]

It is under these conditions that the initial outbreak may have started in Étaples, France at a camp which accommodated approximately 100,000 Allied soldiers in a twelve square kilometre area. The camp was in the vicinity of marsh and farm land, meaning that

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[52] J.S. Oxford, et al., "World War I may have allowed the emergence of 'Spanish' influenza," *The Lancet Infectious Diseases* 2, no. 2 (February 2002): 111; George Dehner, *Global Flu and You: A History of Influenza* (Great Britain: Reaktion Books, 2012), 95, 99.
[53] Oxford, et al., "World War I may have allowed the emergence of 'Spanish' influenza," 111.
[54] Jennifer A. Summers, et al., "Mortality Risk Factors for Pandemic Influenza on New Zealand Troop Ship, 1918," *Emerging Infectious Diseases* 16, no. 12 (December 2010): 1931.
[55] Anton Erkoreka, "Origins of the Spanish Influenza pandemic (1918-1920) and its relation to the First World War," *Journal of Molecular and Genetic Medicine* 3, no. 2 (December 2009): 190.

soldiers were living in the proximity of varied wildlife. Within the context of gas warfare, the soldiers were also exposed to twenty-four different kinds of gasses, which increased their risk of respiratory infection and made them more vulnerable to influenza.[56]

This examination of the 1918 influenza pandemic made use of reports compiled by doctors who were looking after soldiers from France and the United States. References in archival records describing "periodic epidemics" from 1916 to 1918 were also found in medical reports.[57] These reports were held at the *Archives du Service de Santé des Armées*. They also used materials from other archival institutions throughout France, Portugal and Spain to obtain additional information.[58]

What they found was that the first "epidemic wave" of influenza, occurring during the spring in 1918, was benign, as many soldiers contracted influenza but the mortality rates were relatively low. From May to July 1918, nearly 40,000 French soldiers were diagnosed with influenza and thirty-seven died as a result. Over 14,000 American soldiers were affected from April to July of the same year, with no fatalities reported from April to June, and five deaths in the month of July.[59] While influenza was spreading in those months, it did not contribute significantly to the total of forty million deaths which occurred by the end of 1919.[60]

Had influenza been contained, historian of medicine Anton Erkoreka argues that cases of influenza would have been limited to that initial wave and the topic would not attract as much historical attention as it has in the decades that followed. The added

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[56] Annie Prud'homme-Généreux, and Carmen Petrick, "Why Was the 1918 Influenza So Deadly? An Intimate Debate Case," *National Center for Case Study Teaching in Science, University at Buffalo, State University of New York,* March 15, 2012, 2.
[57] Erkoreka, "Origins of the Spanish Influenza pandemic," 192.
[58] Ibid., 191.
[59] Ibid., 192-3.
[60] Oxford, et al., "World War I may have allowed the emergence of 'Spanish' influenza," 111.

circumstance of a war fought on an international scale increased the vulnerability of men exposed to unsanitary living conditions and allowed influenza to spread as the affected population moved to and from the theatres of war.

Other First World War environments have been investigated to assess their impact on influenza vulnerability. One such example looked at the connection between influenza and warships. In the summer of 1918 soldiers on board His Majesty's New Zealand Transport Tahiti (HMNZT) were exposed to an influenza outbreak. The ship traveled from New Zealand to Europe and back many times throughout the war. Over eighty percent of the 1,217 men on board contracted the virus in the summer of 1918. Sixty-eight men died from the illness by September 10th of the same year.[61] On that date, the ship had docked in England and another nine passengers died after disembarking from it. The mortality rate was so great, the HMNZT was nicknamed the "death ship."[62]

Through the use of government reports, a link was uncovered between accommodations and mortality rates. These records were sought out by Jennifer Summers, Michael Baker, and Nick Wilson, researchers in the field of public health at the University of Otago, New Zealand. The on-board environment furthered the epidemic in multiple ways. Records demonstrated that there was "a higher mortality rate for persons in cabins with bunks [...] than for persons in other areas in which hammocks were used." These accommodations were not well ventilated according to inquiry records generated by an investigation of the epidemic in 1918 and consequently, promoted the transmission of influenza via airborne pathogens. Furthermore, the ship was overpopulated, transporting 1,217 soldiers and crew members while designed to carry

[61] Summers et al., "Mortality Risk Factors for Pandemic Influenza," 1932.
[62] Ibid.

just under 700 people.[63] The ship's hospital was also ill-equipped to treat passengers in such large numbers. This meant that the crew could not set up an isolated area to treat patients because they lacked the space to do so.[64]

The archival sources used to investigate the high mortality rates on board the HMNZT were held at the Archives New Zealand, which holds national government records, as well as the Cenotaph database found online through the Auckland War Memorial Museum, where personnel files can be found.[65] These sources were used to obtain contextual information about the events surrounding the outbreak, as well as to identify the affected population and details related to these individuals (age, occupation, place of residence, etc.).[66]

Those investigating the origins and development of the Spanish Influenza have done so with an interest in the study of more current epidemics. Given concern about pandemics raised by recent H1N1 outbreaks, a good grasp of the causes of and responses to past epidemics can contribute to better methods of controlling viruses in the future.[67] Among the lessons that can be taken away from the 1918 influenza epidemic and applied to modern epidemics is "the need to minimise crowding in institutions and others settings; being prepared for future pandemic waves; and planning for 'protective sequestration' in some settings."[68]

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[63] Ibid., 1935.
[64] Ibid.
[65] Archives New Zealand, "What We Have," accessed April 24, 2014, http://archives.govt.nz/has; Auckland War Memorial Museum, "Online Cenotaph Terms and Conditions," accessed March 3, 2015, http://www.aucklandmuseum.com/war-memorial/online-cenotaph/how-to-contribute/terms-of-use.
[66] Summers, et al., "Mortality Risk Factors for Pandemic Influenza," 1932.
[67] Jennifer A. Summers, et al., "Risk factors for death from pandemic influenza in 1918-1919: a case-control study," *Influenza and other respiratory viruses* 8, no. 3 (May 2014): 329.
[68] Nick Wilson, Jennifer Summers, and Michael G. Baker, "Impact of the 1918-1919 influenza pandemic on the New Zealand military and persisting lessons for pandemic control," *Microbiology Australia* 35, no. 3 (September 2014): 138.

Summers et al. have used their study to demonstrate how rapidly illness can spread when there is overcrowding. Based on their findings regarding the spread of influenza on the overcrowded HMNZT ship, they argue that similar consequences could occur in overcrowded institutions, including hospitals. Their study, while based on data that is nearly a century old, emphasizes the need for present hospitals, and other institutions which may face overcrowding, to prepare for epidemics by identifying institutional factors that could aggravate the situation and by developing measures to prevent accelerated spread of disease.[69]

Based on their work with archival records, they have also emphasized the importance of historical sources for epidemiological research:

> Knowledge of pandemic influenza risk factors, the likely speed and pattern of the spread, and the expected impact on a healthcare system, is based on the study of past pandemics. Therefore the understanding of how to use historical records to obtain this knowledge is imperative for such research.[70]

Furthermore, Summers et al. raise the point that the ways in which archives can be used for the field of epidemiology are not self-evident. Users need an understanding of the records themselves and how they can be used. Promoting the uses and value of archival records is just a first step in becoming more visible to the public. New user groups, less familiar with archival records, will not greatly benefit from them if archivists simply give physical access to the records and leave users to figure out how to best use them. Without an understanding of how these records can be used, users will not fully benefit from

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[69] Summers et al., "Mortality Risk Factors for Pandemic Influenza," 1935.

[70] Jennifer A. Summers, Michael G. Baker, and Nick Wilson, "Historical Approaches in Studying Past Influenza Pandemics: The Value of Military Archival Sources," (poster presentation, Influenza 2012 Conference, Oxford, UK, September 2012).

archival sources and archivists will lose potential archival advocates in the process. Consequently, it is important to recognize the limits of a user's archival knowledge.

Some professions are more familiar with archival research as their work requires a strong relationship with archives. Historians rely on primary sources to create and substantiate their narratives. As a result of this work, they develop knowledge of archives at the earliest stages of their professional lives as they work with the primary sources they require for their research. Genealogists turn to archival institutions to track family histories. Genealogical societies and books targeting beginners in the field of genealogy offer support for individuals who have little or no experience working with archival sources.[71]

But user groups with relatively less experience with archives do not have those same sources of support in place. In their analysis of archival research expertise, Elizabeth Yakel and Deborah A. Torres assert that researchers need different levels of knowledge to conduct their research with greater efficiency. One type of knowledge that they should have is "archival intelligence," or

> knowledge of archival principles, practices, and institutions, such as the reasons underlying archival rules and procedures, how to develop search strategies to explore research questions, and an understanding of the relationship between primary sources and their surrogates.[72]

New users will often be unfamiliar with archival language, which can create barriers to research. Despite being called an access tool, a finding aid will not facilitate access if

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[71] See, for example, Anne Bruner Eales and Robert M. Kvasnicka, *Guide to Genealogical Research in the National Archives* (United States: National Archives and Records Administration, 2000); John P. Deeben, *Genealogy Tool Kit: Getting Started on Your Family History at the National Archives* (United States: Foundation for the National Archives, 2012); Stella Colwell, *The National Archives: A Practical Guide for Family Historians* (Great Britain: The National Archives, 2006); National Archives of Scotland, *Tracing Your Scottish Ancestors: A Guide to Ancestry Research in the National Archives of Scotland* (Edinburgh: Mercat Press, 2008).

[72] Elizabeth Yakel, and Deborah A. Torres, "AI: Archival Intelligence and User Expertise," *The American Archivist* 66 (Spring/Summer 2003): 52.

users do not understand its terminology.[73] For this reason, it is all the more important to forge relationships with users coming from fields with a relatively short history with archives as they might not only lack "archival intelligence" but also lack the support systems they need to obtain it.[74]

Even when new users' skills seem to conform with practices required when consulting archives, they might not be inherently compatible. For example, users interested in health might consider themselves as being expert researchers, but while they might have significant experience conducting research in their own field, rules applied to the archival environment might conflict with their previously developed research habits. Having to wait for assistance when another box is needed as opposed to simply pulling the required item off a shelf as a user would in a library, for instance, might interrupt a user's research flow. As Yakel and Torres argue, rules need to "become routine" as otherwise, they can distract the user from their research.[75] Yakel and Torres further state that it is important for both researchers and reference archivists to be able to "identify the limits of knowledge in others." [76]

Different users will need different levels of assistance. Similarly, reference archivists might be experts in some areas but may require more information from some users if they have never dealt with similar queries or even similar users. And while having archivists coming from more diverse fields outside of the humanities might resolve this, smaller institutions which rely one a one-person staff due to limited resources cannot expect a single person to possess all the knowledge and skill-sets that

[73] Ibid., 64.
[74] Ibid., 52.
[75] Ibid., 66.
[76] Ibid., 67.

could potentially be useful when dealing with new incoming users. Thus, the best option for archivists in this position is to use these interactions with new and foreign user groups as opportunities for engagement and development.

Understanding what each party needs will also make the research process more efficient. Archivists who have never worked with epidemiologists before, for example, can provide better support for these users if they prompt users for more information, not only about what they are researching but how they research. Archivists can then assess their working relationship with these users and identify both areas where their institutions act as facilitators or impediments to research so that archivists can work around and avoid becoming the latter.

If research space at the archives is not suited to the users, then other suitable locations could be discussed and considered. Or, if record formats are not practical, archivists could offer to have these records converted to a different format to make them more accessible. If such a solution is suited to the user, further discussions could be taken to arrange funding for this type of project, where the users would provide funding to hire an archivist who would work specifically on facilitating their research process. By minimizing barriers to research, archivists will be better able to ensure that researchers have a successful experience.

Working with new user groups to assess their specific research interests and needs can be beneficial to both parties. Beyond improving the aspects of "archival intelligence" mentioned above, there are other areas of archival knowledge that could facilitate the research process for both archivists and users.[77] Understanding the resources of time, money, and staff involved in providing reference services, retrieving records, making

[77] Ibid., 52.

them available, making photocopies, and scanning documents could give new users a better sense of what archivists do. That, in turn, could lead to more arrangements similar to the allocation of funding for archival services provided by researchers working in Snowdon's Nun Study.[78]

For new users, establishing a good, supportive relationship during the research process puts forward a good first impression of archivists and archival institutions. In turn, users have a positive experience working with archival records. Users such as Summers, Baker and Wilson, have found such valuable information in archival records that they recommended more epidemiologists look to these sources when studying epidemics. Attracting a wider variety of users, coming from different fields, has the potential to increase archival visibility. It is therefore imperative that archivists ensure that new users have a good experience with archival records so that they are keen to return and might then generate greater archival visibility by encouraging their respective professional communities to explore the archives as well.[79]

This thesis has so far examined the value of using existing archival records. A final example related to the study of Gulf War Syndrome will demonstrate the value of archival work by examining what happens when records cannot be used because they are unavailable to users. This was the fate of records related to the 1990-91 Gulf War whose value was not sufficiently recognized at the time of their creation. As a result no proper steps were taken to ensure their preservation.

In its aftermath, veterans of the Gulf War began to report ailments which included:

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[78] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 92.
[79] Pugh, *Providing Reference Services for Archives and Manuscripts,* 40.

> chronic fatigue, muscle and joint pain, cutaneous rashes, gastrointestinal disturbances, respiratory disturbances, headaches, difficulty in concentrating, memory loss, irritability, and depression.[80]

Furthermore, many children of veterans were also born with birth defects.[81] A study has also shown that veterans of the Gulf War have an increased risk of developing lung cancer. The latter study used multiple sources, including records archived by the *Defense Manpower Data Center,* a centre that operates under the U.S. Department of Defense to archive military personnel records for administrative purposes such as health care and retirement issues.[82] Though records such as these have been successfully tracked and accessed by researchers, many other records have been lost. This has created a significant barrier to learning about the causes of the syndrome.

Military records could corroborate a theory which suggests that exposure to toxins released in the air, including smoke produced from oil fires, or subjection to depleted uranium and exposure to pesticides and sarin may be among suspected causes of the syndrome.[83] To support this theory, more evidence is needed. Military field records could detail the surrounding environments of veterans who are suffering from Gulf War Syndrome. If field records reveal that veterans now suffering from the illness were near the oil fires at a given point in time, it could help substantiate the claim that such toxins may be linked to the syndrome.

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[80] Chantal Bismuth, and Andreas Schaper, "Gulf war syndrome," in *Treating Victims of Weapons of Mass Destruction: Medical, Legal and Strategic Aspects,* eds. Patrick Barriot and Chantal Bismuth (England: Wiley, 2008), 65.
[81] Simon Wessely and the King's College Gulf War Research Unit, "Ten years on: what do we know about Gulf War syndrome?," *Clinical Medicine* 1, no 1 (January/February 2001): 28.
[82] Heather A. Young et al., "Investigating the Risk of Cancer in 1990-1991 US Gulf War Veterans With the Use of State Cancer Registry Data," *Annals of Epidemiology* 20, no. 4 (April 2010): 265.
[83] Wesseley and the King's College Gulf War Research Unit, "Ten years on," 30.

The loss of records from the Gulf War has resulted in delays in finding answers to queries about Gulf War Syndrome.[84] The devastating impact of that on medical knowledge has been felt by government officials, who have undertaken an initiative to reconstruct these records to learn more about the causes behind the symptoms.[85] Officials have had to interview commanders to reconstruct accounts in order to find out whether exposure to toxins emitted from smoke after a nerve gas explosion may be linked to many of the symptoms present in soldiers diagnosed with Gulf War Syndrome.[86] Information that would reveal the location of soldiers throughout the war, and thus their proximity and exposure to toxins, would prove especially useful.

The U.S. army has investigated the issues that have led to such a significant loss of data. These efforts have been time consuming and costly. Consequently, the importance of proper record keeping has been recognized by the army but this only came after what is referred to as the occurrence of a "virtual collapse of the Army's operational records keeping system."[87] The improper record keeping and failure to preserve records such as these can seriously limit what we can learn from the past. Previous studies using archival data have disqualified participants from their studies because of missing data. For instance, studies related to the Dutch famine have had to eliminate participants if relevant data related to them could not be obtained.[88] However, missing data, in the case of the Dutch study, was not significant enough to prevent the study from going forward.

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[84] U.S. Army (AAMH-ZC), Army Operational Records, Data Collection, and Readiness, February 20, 2009, 3.
[85] Peter Sleeth and Hal Bernton, "Lost war-zone records add to veterans' pain," *Seattle Times,* November 10, 2012.
[86] U.S. Army, Army Operational Records, 4.
[87] Ibid., 2.
[88] Stein et al., *Famine and Human Development*, 58.

The significant loss of data created during the Gulf War, on the other hand, has presented a much greater obstacle to knowledge.

The only method of prevention in this case is thoroughness on the part of those creating and maintaining the records. In the digital age, especially, it becomes crucial for archivists to be at the forefront of records creation, working with record creators and managers to ensure that when records reach the archival stage, they are in fact available and useable. Gulf War records could have potentially held answers which would have had important implications for the health of veterans. But despite the power that archival records can hold, they are embodied in particularly fragile mediums, making them vulnerable and destructible. The shift to more digitally-focused records creation has not increased the durability of the record, but rather, it has weakened it considerably.

While paper records potentially have the ability to survive in less than ideal conditions for decades, digital records have an average lifespan of approximately ten to fifteen years.[89] Only constant close attention to the need to move them into still active and supportive technological systems enables us to hope to preserve them across time. The relatively short life of digital records and the risks that can jeopardize their integrity validates the view of archivists such as Jay Atherton that archivists should be actively involved at the records management stage even before records are created.[90]

The loss of information, particularly in the digital age, can severely hinder health-related research. Military records have contributed much to the health-related research, as the above discussion of U.S. Civil War records has shown, and even in regard to

[89] Kastellec, "Practical Limits to the scope of digital preservation," 63.
[90] Jay Atherton, "From Life Cycle to Continuum: Some Thoughts on the Records Management-Archives Relationship," *Archivaria* 21 (Winter 1985/86): 47.

influenza research.[91] Military records typically provide researchers with both quality and quantity in terms of information. Quality, as military records include consistent forms such as regimental, pension or service records, documenting consistent information from one individual to the next, and quantity, because this information is available in heavy volumes and translates into a larger study population. However, military data from the Civil War was extracted from analog records while military records which could hold insights into health conditions today are increasingly born digital. The war in Iraq launched in 2003 is considered to be the first war for which all its records were intended to be stored on computers.[92] But millions of electronic records generated in this and the Gulf War cannot be located or have been destroyed by military personnel.[93]

This negligence is principally due to carelessness which is often fuelled by a keenness to jump on the digital or electronic records 'bandwagon.' Here, the focus is often on the strengths of digital record keeping – the paperless environment, the ability to transcend geographic barriers when sending or sharing files – but equal focus is not always given to the systems which need to be implemented to ensure that electronic records of enduring value can be preserved so that they may be accessed ten, twenty, fifty years down the line and beyond. In terms of records management, processes and retention and disposition schedules are not always well-established or altered in consideration of digital records, if any are developed at all.[94]

Due to such oversights, the U.S. army has been forced to revise its record keeping practices. This work involved establishing better systems for records management and

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[91] Noymer, "Testing the influenza-tuberculosis selective mortality hypothesis," 1602.
[92] Peter Sleeth, interview by Jeffrey Brown, *MacNeil/Lehrer, Newshour*, PBS, November 12, 2012.
[93] Ibid.
[94] Donald Fisher Harrison, "Computers, Electronic Data, and the Vietnam War," *Archivaria* 26 (Summer 1988): 26.

disposition, and offering better training for those responsible for records care.[95] To assess problem areas in records management, a War Records Working Group, which included records managers and archivists from NARA, was sent to Baghdad in the spring of 2010 to survey the record keeping situation.[96]

The working group identified several problems, including that staff they consulted often "reported knowledge of only the recently created and filed records and knew little of the records created prior to their deployments" and that consequently, it was "unclear the extent to which records exist[ed] prior to 2006."[97] Records management standards were not in place until 2008, approximately five years after the war in Iraq began. Furthermore, processes for records disposition were not set, bringing into question how records would be transferred back to the U.S. after the war.

The value of records and the importance of preserving them is clear based on all the efforts undertaken to assess the deficiencies within the U.S. military's record keeping systems and to resolve the issues created by a loss of information. However, these actions were necessary because the value of records was overlooked in the first place. The efforts taken to retrieve and re-create missing records show that the value of records was only recognized reactively. This case perhaps best shows how archives can go unnoticed among the public. The value of these records was not recognized as they were being created. Beyond their immediate use, not enough consideration was given to their future uses. Only when the absence of records generated problems by complicating matters

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[95] U.S. Army, "Army Operational Records," 1.
[96] Peter Sleeth and Hal Bernton, "Lost to History: Missing War Records Complicate Benefit Claims by Iraq, Afghanistan Veterans," *Seattle Times,* November 9, 2012, accessed October 21, 2014, http://www.propublica.org/article/lost-to-history-missing-war-records-complicate-benefit-claims-by-veterans.
[97] Michael "Carlson, NARA Trip Report," April 15, 2013, accessed October 21, 2014, http://www.propublica.org/documents/item/403775-nara-trip-report.

related to claims processes, historical research, research into Gulf War syndrome, and so on, were measures taken to investigate and correct the situation.

It is crucial that records creators recognize the long-term value of the records they generate and maintain. Here, archivists can perhaps adopt a proactive approach, discussing the long-term value of records and methods of preservation with records creators before records are even created. If creators understand that the records they create have potential uses that they as creators may not anticipate, they may better grasp the full value of the records they create and ensure that these are properly kept and organized before they reach the archives.

Researchers who have recognized the variety of ways in which records preserved by archival institutions can be used have gone on to support both archival institutions and archival research. Funding to encourage further archival research using information extracted from Civil War records was obtained by the creators of the Union Army Database.[98] Snowdon allocated a portion of his grant money to the SSND convent to ensure that research support for Snowdon's study would not come at the expense of the archive's day-to-day functions and management.[99] If record creators came to appreciate the diverse ways in which their records could potentially be exploited, they could, like users of such records, recognize the value in them and find ways of supporting preservation efforts in similar ways. This, in turn, could facilitate preservation of and access to these records at the archival stage.

Those military records which detail events of war might later be useful to study the causes of certain illnesses prevalent among veterans. Convent records might be

[98] "Union Army Data – About Us," http://www.uadata.org/about/.
[99] Patzwald and Wildt, "The Use of Convent Archival Records in Medical Research," 92.

created and maintained for organizational purposes but could later reveal a documented history of isolated living and its connection to health, causing some to re-assess vaccination policies. Population registries may be developed to document and keep track of vital statistics but they might unveil a connection between power lines and leukemia in children, triggering international discussions on electromagnetic safety standards. Military records of the First World War might document the movement of soldiers to and from the battlefield but could later reveal living conditions conducive to the spread of an international epidemic and provide researchers with insights into how best to confront present and future outbreaks.

Despite these impressive connections between archives and health-related knowledge, these uses were never anticipated when the records were first created. The fact remains that record creators do not always grasp the full value of the records they create. An underappreciation of archival value can jeopardize the ability of archivists to do their work if, as a result, those records are not properly managed before they are transferred to the archives.

If the public does not appreciate the value of current records then they may well be lost to future generations, particularly if they are in digital form. Archivists need to communicate the importance of the work they do so that future records of historical significance can be preserved. But to whom are these records significant? Why are they significant? If the public cannot answer these questions then it cannot fully comprehend the value of archival records. To ensure that the value of archival work is understood, archivists need to answer those very questions.[100]

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[100] Kathleen Roe, "Let's Give Them Something to Talk About: Advocating for Archives," *Provenance* 28, no. 1 (2010): 7.

Conclusion

In her article on advocating for archives, Kathleen Roe argues that while archivists often speak to the public about the "treasures" to be found in their holdings, many archivists fail to address the "so what?"[1] They talk about interesting record types (e.g., old maps, glass slides, detailed diaries) and their fascinating contents, but do not directly address why they are valuable or how these records can be used. Of course, archivists understand that there is something to be gained from using archives. However, when communicating with the public, either directly or through traditional and social media, it seems that the message conveyed is intended to elicit an "ooooh aaaaah" effect rather than to publicize the greater societal benefits of archives.

If archivists wish to advocate for the use of the holdings they work with, then they must promote the "so what?" to which Roe refers – or the actual outcomes and impacts of the uses of archives.[2] As stated by Richard Pearce-Moses, "effective advocacy is less about pleading for support and more about explaining the benefit of archives" which "should focus on a positive expression of the value of archives."[3] Promoting actual uses of archival records and the impact of those uses is the best chance the profession has to show the merit of its work. Simply looking at the realm of health, archivists have many examples of archival value to convey to their users. Archival research linked to cardiovascular health, mental development, trauma, diabetes, cancer, genetic inheritance, epidemiology, malnutrition, and so on, all provide concrete evidence of the benefits of archives. Records useful to these topics and discussed in this thesis have been found at

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[1] Ibid.
[2] Ibid.
[3] Richard Pearce-Moses, "Finding our Voice: Pleading the Value of Archives," *Provenance, Journal of the Society of Georgia Archivists* 31, no. 1 (2013): 4-5.

the National Archives and Records Administration (U.S.), the Beethoven-Archiv (Germany), the Archives du Service de santé des armées (France), the City of Amsterdam Archives, the Yad Vashem Archives (Israel), the Hertfordshire Archives and Local Studies (England), the Danish National Archives, Archives New Zealand, and the Stockholm City Archives, to name just a few. Archival research related to health has not only been conducted in different countries throughout the world but the results of this research have also been disseminated to the public in various media, including television, radio, newspapers, magazines, books and scholarly journals on an international scale.

Barker's hypothesis, Feychting and Alhbom's powerline study, the revision of the NVVRS, and the effects of famine on transgenerational health are only a few positive expressions of archival value which have resulted in significant and far-reaching impacts. Archives have also allowed researchers to learn more about and to build awareness of illnesses such as PTSD. Past misdiagnoses have been clarified while, in other cases, archives have been used to trigger discussion and create spaces conducive to healing. There are many other positive examples of health-related uses of archives.[4] Archivists therefore might do much more to understand these remarkable findings and make them better known.

[4] Other examples of archival uses for the study of medicine include: the use of death certificates from the New York City Municipal Archives to determine whether there was a connection between the smallpox vaccine and cardiac deaths: Lorna E. Thorpe, et al., "Mass Smallpox Vaccination and Cardiac Deaths, New York City, 1947," *Emerging Infectious Diseases* 10, no. 5 (May 2004): 917-920; the use of family histories from the archives of the Utah Family History Library integrated into the Utah Population Database to study various topics related to epidemiology and genetics: http://healthcare.utah.edu/huntsmancancerinstitute/research/updb/ (accessed February 28, 2015); school health records of 350,000 students who attended schools in Copenhagen between 1930 to 1983 have been integrated into a database used to study obesity, multiple sclerosis, and cancer: Jennifer L. Baker et al., "Cohort Profile: The Copenhagen School Health Records Register," *International Journal of Epidemiology* 38, no. 3 (June 2009): 656-662.

Without archival sources, some studies could not proceed and some findings could not be reached. For example, works focused on the study of famine, or of trauma, cannot create the conditions they are studying because it would be unethical to starve subjects or forcibly remove children from their parents in order to study the effects. Records generated from past events where such events occurred naturally allow researchers to overcome ethical barriers by conducting retrospective studies.

Records can provide information on specific events such as births, deaths, marriages, descendants, and employment. Piecing these records together allows researchers to reconstruct the lives of their study population by connecting the progression or regression of their health to specific 'check points' throughout their lives. Linking these separate yet related events digitally can make easier the process of data collection for users.

Both archival records and sources external to archives can provide useful checkpoints which can be linked to create a fuller picture of health:

> [R]esearchers may not just be interested in archives. Indeed, they may not really have thought about using primary source material, but they may be very interested in biographical information, known and unknown connections, events during a person's lifetime, etc. [...] [A]rchives can benefit from being presented not in isolation, but as a part of all of the diverse data sources that can be found to create a full biographical picture, and to enable researchers to make connections between people and events to create different narratives.[5]

Some of the examples in this thesis have benefitted from connecting different sources to compile a life history for retrospective study participants. The Union Army data sets, for example, have compiled sources such as surgeons' certificates, regimental records, census information, carded medical records and pension records. These sources are all

[5] Adrian Stephenson, "LOCAH continues as the 'Linking Lives' Project," LOCAH Project (April 30, 2012), accessed December 2, 2014, http://archiveshub.ac.uk/locah/2012/04/30/linking-lives-project/.

presented in a format that is available to interested users and where the resulting data sets are flexible enough so that they can be used for multiple purposes and applied to many fields such as economics, sociology, and health.

In other studies, relevant information came from various sources and was not compiled or connected in a central, digitally available location. For instance, Feychting and Alhbom obtained maps providing information on power lines from the Swedish Central Board for Real Estate. They then collected information from population registries held by the Stockholm City Archives. Furthermore, they made use of a Swedish cancer registry from the National Board of Health and Welfare. Any hospital in Sweden that treated study participants diagnosed with cancer was also contacted so that relevant medical records could be obtained. Finally, a mortality registry was consulted through the National Central Bureau of Statistics. The tools to centralize all this information into a single database or to link multiple records created by varying sources are available and can facilitate research in so many ways. Furthermore, these databases can be designed for various users.

The creation of such databases is not an inexpensive process and can be very time consuming. However, the value of these databases makes the effort to create them worthwhile. Advocating for the use of archives for health-related research can also help attract users who have the means to undertake larger projects and create a database that is accessible for them, but also to others. The creators of the Union Army data sets saw value in the records held at NARA for themselves but also for others. As a result, they made their databases available online to any interested users.

Elements can also be put in place to minimize barriers when using these databases. For instance, the creation of initiatives such as the *Clinical Practice Research Datalink* (CPRD) can make easier the process of accessing confidential records. In the U.K., the government has recognized the impact that records-based studies have had on their nation. These include discrediting the belief that the MMR vaccine, which immunizes against measles, mumps, and rubella, could cause autism, and improving cancer survival rates in England through early diagnosis.[6] This has led the U.K. government to attempt to simplify the process of developing records-based studies through the creation of the CPRD. This database links patient records from the *National Health Service* to doctor's offices and hospitals, as well as to disease, mental health and genetics registries and databases.[7]

Researchers who make use of this database will not be discouraged by roadblocks they may face because of confidentiality issues. All records in the database have been anonymized and the information on anyone who is registered in the NHS system becomes potential research material by default. Initiatives such as these can help create greater opportunities for researchers seeking to conduct records-based studies which could involve privacy issues.[8] The creators of this system hope that by facilitating access to these records for researchers, medical advancements will be furthered and the overall impact will be greater. While the CPRD mainly compiles medical records, its creators are considering integrating other records such as "pollution data [and] social care records."[9]

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[6] Ian Sample, "NHS patient records to revolutionise medical research in Britain," *The Guardian*, August 28, 2012.
[7] Ibid.
[8] Ibid.
[9] Ibid.

The use of records generated by medical institutions in the U.K. for the study of health has been valued to the point that the government supported the CPRD initiative "to encourage a surge in studies that draw on public health records."[10] However, health records are very narrowly defined. In the archival environment, medical records take on a definition that goes beyond documentation generated by healthcare providers. Parish records, photographs, population registries, military records, school files and convent records, for example, can all provide insights into health. While medical records, in the narrow sense of those that contain actual medical information, provide valuable support for the study of health, archival records can provide equally significant information.

Archival records have helped to "launch a medical revolution," they have proved to be an "invaluable," "promising" source of inspiration for research and have provided users with "unique" opportunities to study health.[11] Their value is apparent in the examples explored throughout this thesis of medical findings re-examined through an archival perspective. The broader impact of such research is implicit in discussions of epidemiology. Research in that field, for example, has a reach that extends beyond the field of epidemiology as "findings have major political, economic, and social implications" which can be "used and applied by many people outside the field, including legislators, regulators, [...] lawyers and journalists."[12]

The introduction to this thesis put forward a question: what can users who seek archival sources to conduct investigations into health problems contribute to the archival

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[10] Ibid.
[11] *Horizon*, "The Ghost in Your Genes"; Elliott and Wartenberg, "Spatial Epidemiology," 1003; Wimmer, "Reflections on the Early Indicators Project," 4; Elder, Jr., Pavalko, and Clipp, *Working with Archival Data*, 6; Pesonen, et al., "Depressive Symptoms in Adults Separated from Their Parents as Children," 1132.
[12] Leon Gordis, "Challenges to Epidemiology in the Next Decade," *American Journal of Epidemiology* 128, no. 1 (1988): 1.

profession? They can provide concrete examples of why archives are valuable to society and reach a wide audience with this message in scholarly journals, books, documentaries, and the news media. Moreover, these researchers can provide an opportunity for archival introspection. Authors who have praised archives, such as Dr. Snowdon, seem to have established a more personal relationship with archivists but also with the archive itself. Snowdon's book makes many references to the archive, its records and its staff, and he even expresses a sense of awe and admiration in each of these references.

The autobiographies he uses are not simply records, but "miraculously preserved fragments of the past."[13] His ability to access the convent archives did not simply facilitate research but enabled "the most powerful Alzheimer's studies in the world" to go forward.[14] He describes being welcomed into the archives and his feeling of excitement while receiving a tour from archivist Sister Marjorie Myers.[15] He understands and appreciates the work that went into preserving and storing the records found in the archive.[16] Clearly, the SSND archive made an impression on Snowdon and as a result, he transfers that impression onto his readers – the SSND's "indirect users" – as he outlines for readers of *Aging with Grace* the value of archives.[17] His work not only references the archive but praises it. The question is, how do we instil in all users, this same sense of appreciation and understanding of archival value?

What is clear is that the SSND archivists made an impression on Snowdon. They established a close working relationship, in which the archivists engaged with Snowdon, learned about his research needs and, based on that information, assessed the feasibility

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[13] Snowdon, *Aging with Grace*, 106.
[14] Ibid., 51.
[15] Ibid., 24.
[16] Ibid., 65.
[17] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.

of supporting his work and made arrangements to overcome obstacles such as funding and access, by accepting funding from Snowdon to hire additional staff and by allowing materials to be taken off-site.[18]

It is very unlikely that these convent archives had ever before been used in the study of epidemiology when Snowdon approached the SSND convent. While the SSND archivists most likely did not know much about epidemiology, Snowdon's research did not expose a weakness in the archivists' knowledge but rather a strength. They might not have understood where Snowdon was coming from when he first asked about the archives but, through dialogue and cooperation, the archivists developed their knowledge and showed a strong sense of commitment to helping their users.

With growing, more wide-ranging uses of archives, there is an opportunity, not only to increase public awareness of archives and to promote their societal value, but also for archivists to increase their knowledge of archival users coming from different fields. Consequently, when these new and more foreign user groups do come knocking at the doors of the archives, archivists should be prepared. This is not to say that archivists should already have a strong knowledge of these new and/or unfamiliar user groups. While this in any case would be an asset, it is unreasonable to expect, not to mention impossible for archivists to anticipate all uses and build their awareness of the research needs of each potential user accordingly. Rather, archivists should be prepared to engage, openly and honestly with new user groups.

To engage in such a way, archivists need to make a positive impact on their users by demonstrating both the potential value and also concrete examples of archival use. At the same time, archivists should acknowledge the limitations and barriers they may face,

[18] Patzwald, and Wildt, "The Use of Convent Archival Records in Medical Research," 92.

such as access limitations or restrictions in terms of resources of time, staff and money, while also showing their commitment to help users overcome them where possible.

Archivists such as Megan Sniffin-Marinoff have offered useful suggestions about how archivists could promote their holdings and institutions that are relevant to the examples of medical research discussed in this thesis. She suggests that archivists advertise their "uniqueness."[19] The unique nature of archives is conveyed and promoted by Pesonen et al. in their study of child-adult separation.[20] Surgeons' Certificates and Pension records have been described by the creators of the Union Army database as the "most valuable records and those making [the] study unique."[21] The records in Överkalix provided a "unique opportunity" to study epigenetics.[22]

Sniffin-Marinoff further suggests that archivists might utilize the media to convey a "friendly image."[23] Such an image is conveyed in Russell Martin's book on the retrospective diagnosis of Beethoven as the "dedicated assistance" of archivists searching their holdings and databases to support the work of Brilliant and Guevara.[24] It is also conveyed by Snowdon in his description of meeting and working with the SSND archivist, Sister Marjorie Myers.[25] Archivists might also inform the media about "a new facility or new equipment allowing better access." Larry T. Wimmer's chapter on the

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[19] Megan Sniffin-Marinoff, "In Print, On Air: Working with the Media," in *Advocating Archives: An Introduction to Public Relations for Archivists*, ed. Elsie Freeman Finch (Metuchen, N.J.: Scarecrow Press, 1994), 49.
[20] Pesonen, et al., "Depressive Symptoms in Adults Separated from Their Parents as Children," 1132.
[21] Wimmer, "Reflections on the Early Indicators Project," 4.
[22] Nova, "Ghost in Your Genes."
[23] Sniffin-Marinoff, "In Print, On Air," 49.
[24] Martin, *Beethoven's Hair*, 197, 211.
[25] Snowdon, *Aging with Grace,* 24, 28.

Union Army Database advertises the creation of an online database which facilitates access to a significant volume of valuable data.[26]

Lastly, Sniffin-Marinoff proposes that archivists promote an upcoming "conference on a controversial subject."[27] While archivists could promote such events, so could users such as Feychting and Ahlbom promote the significance of archives to their groundbreaking work in conferences such as the Department of Energy's conference for Electromagnetic Field researchers in San Diego where their work was the focus.[28]

These examples demonstrate how direct users can be allies to archival institutions in multiple ways. They can perform outreach activities through the publication of their works. They can help provide funding so that archivists can better assist them. They can be advocates, promoting the value of record preservation and archival work and use. However, to share in these roles and assist archival institutions, archivists must understand what these users need, how they conduct their research, and find out what archival value means to them.

It is also important to consider that individuals who interact with archives in different ways can assume multiple roles.[29] "[I]ndirect users" who encounter and benefit from stories about uses of archives in the media might themselves become direct users of archives.[30] Users of archives might become advocates for archives. They might also become funders to support continued use of archival research. They might become donors, giving their data to an archival institution once their research is completed.

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[26] Wimmer, "Reflections on the Early Indicators Project," 1-10.
[27] Sniffin-Marinoff, "In Print, On Air," 49.
[28] Maugh, "Studies Link Electromagnetic Fields, Cancer."
[29] Elsie Freeman Finch and Paul Conway, "Talking to the Angel: Beginning Your Public Relations Program," in *Advocating Archives: An Introduction to Public Relations for Archivists*, ed. Elsie Freeman Finch (Metuchen, N.J.: Scarecrow Press, 1994), 6.
[30] Pugh, *Providing Reference Services for Archives and Manuscripts*, 37.

Equally important to consider is how well-equipped archives are to receive individuals in all of these roles. Medical researchers who seek to donate their data to an archival institution, for instance, may take note of the fact that many traditional archives tend to disregard scientific data.[31] They do not actively seek it out, nor do they consider data to have enduring value when it does come to them – seeing these data as preliminary to the final findings or transitory. They do not see the value that individuals such as Elder, Pavalko and Clipp see in asking "new questions of old data."[32] Data can have long-term use beyond the conclusion of the research that generated it and, fundamentally, "[a]rchives exist to be used."[33]

However, this thesis has mainly examined studies which have used analog records typically held in archival institutions. Military records, population registers, parish and convent records, are not uncommon record types for national, municipal and religious archives. Furthermore, these records, while having value for the sciences, are not generated by the sciences. Users such as Bygren and Pembrey, Barker, Thomas, and Summers et al. have turned to analog records, not necessarily because of a personal preference, but because they required evidence which documented events over a lifetime, or over several lifetimes. As born-digital records are only part of our relatively recent past, the significant period that they are looking at is mainly documented through analog records. While many archivists might contend that they are more comfortable dealing

[31] Dharma Akmon, et al., "The application of archival concepts to a data-intensive environment: working with scientists to understand data management and preservation needs," *Archival Science* 11, no. 3-4 (2011): 330.
[32] Elder, Pavalko, and Clipp, *Working with Archival Data,* 6.
[33] Alex Poole, "How has you science data grown? Digital curation and the human factor: a critical literature review," *Archival Science* 15, no. 2 (June 2015): 114.

with these types of documents, their users have still highlighted some limitations of accessing and using paper-based records in both subtle and more obvious ways.[34]

And so, if users are already encountering research barriers with analog records common to many archival institutions and which document common functions – population development, organizational histories, military logistics – such barriers will only increase when medical researchers request access to scientific documents which many archivists, trained in the humanities, approach with "discomfort."[35] Similar barriers will be met by researchers as they begin requesting electronic data. And, as current and future generations decreasingly see their lives documented in paper-based records, these requests will become more common going forward.

With a growing and increasingly diversified set of users, archives may need to re-consider what they acquire, how they appraise incoming records and what types of records they value through appraisal, and how they manage and allow access. Re-examining archival functions as they apply to different user groups may reveal that many archival functions may favour some users over others. To support greater use and archival visibility, it is important to examine the limits of current practices as they relate to different user groups to ensure that archival use is facilitated for each user group, rather than made more difficult.

Working in institutions of memory, archivists become memory mediators.[36] This responsibility goes beyond ensuring the preservation of memory but ensuring that these

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[34] Barker, "The midwife, the coincidence, and the hypothesis," 1428; Feychting, and Ahlbom, "Magnetic Fields and Cancer in Children," 469.
[35] Jill Delaney, "An Inconvenient Truth? Scientific Photography and Archival Ambivalence," *Archivaria* 65 (2008): 90.
[36] Joan M. Schwartz, and Terry Cook, "Archives, records, and power: The making of modern memory," *Archival Science* 2, no. 1-2 (March 2002): 2.

memories do not lie dormant, unused and inaccessible. These memories must be actively exploited for the benefit of the greater public.[37] Exploited and re-interpreted, the recorded memories of English midwives can provide insights into heart health. The memories of Indian Residential Schools survivors and administrators can trigger discussion of social injustice and healing. The memories of Dutch nuns can help to advocate for the importance of vaccinations and booster shots.

For medical researchers whose research might benefit from archives, a significant obstacle may be that they have never even considered archives as a valuable source of information, as archives are likely to be foreign to them. Value takes on different meanings for different user groups. Each user will interpret records in different ways and interpret their value accordingly. To ensure that archival records are valued and exploited to the greatest extent, archivists, as mediators, need to learn about the varieties of research being done, and whether archives might be useful to them.

Archivists also need to learn from new incoming users and offer support along the way so that each one finds value in archival research. And if they fail to instil in their users a sense of value, then these users will, in turn, fail to instil in their audience the benefits of archival research and the importance of archival work. However, if we make archives more visible and accessible to new user groups, then this exposes archival records to diverse interpretations from researchers with different sets of interest, expertise, and knowledge which in turn, may help reveal greater insights and the greater potential of archival information. By welcoming new users and making easier the

[37] Yvon Lemay, Louise Gagnon-Arguin, eds., *L'archiviste: Constructeur et Communicateur* (Canada: Presses de l'Université du Québec, 2009,) 78.

research process, not only will we maximize archival use but we will also ensure that archives can reveal their full potential to a greater public.

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