Digging into Death Certification Data to Uncover Family History and Family Health Treasures – A Physician's Perspective

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Introduction

Death documentation in the US can be a gold mine of information for the person interested in family history. Information such as date of birth, date of death, birthplace, parents, surviving spouse, can be used to identify people and link them to family trees. Recording our cause of death is a relatively recent human endeavor as we shall see and of the 50 million people who die worldwide each year, only half will have their death officially documented. Even in the 21st century, those living in the less developed countries are likely to not have their death recorded let alone cause of death. (1)

From a medical perspective, collecting causes of death on a national level helps shape medical research, health care funding, and public health policy. Life expectancy in the US in 1820 from birth was 44 years and in 2020 had increased to almost 80 years in good part due to the collection and analysis of death data.

Recognizing medical conditions that are common in your family using death registration information might prove useful to identify risk of developing certain diseases in time to modify that risk. With our current medical and epidemiological understanding of disease, our ancestors can speak to us from the dust and warn us disease if we will take the time to find the right information.

Our purpose in this review is to discuss the fascinating history of death recording, discuss the death data collected in the US that includes cause of death such as mortality schedules, state and county death registries, and the modern death certificate. Finally, we will review some of the common diseases that have a strong genetic component which the family historian should look for during their work to understand and potentially modify their own

medical future as well as the medical future of their descendants. To do that we will discuss creating your own family medical portrait that allows us to calculate risk of common genetically influenced diseases. Because of this end goal we will restrict our discussion to death information where cause of death and other medical information is available.

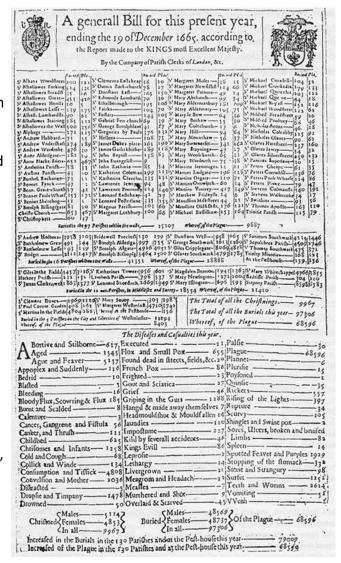
Section 1: History of Recording Death and Causes of Death

One would think that civilizations that could build pyramids like the Egyptians, mastered philosophy, mathematics, and medicine like the Greeks, or who were able to administer the largest empire of the ancient world and were exceptional builders and engineers like the Romans, would have recognized the potential benefit of recording causes of death. We often have dates of death for prominent ancient personalities but rarely their cause of death. There are notable exceptions such as Gaius Julius Caesar who died on March 15, 44 BC whose immediate cause of death on a modern US death certificate would be hemorrhage as a consequence of multiple stab wounds and the manner of death would be listed as homicide. Ancient physicians such as Galen wrote about, and modern science have identified common diseases afflicting people who lived anciently. We also know from historical writings of the episodic plagues that decimated civilizations. A good example is the so-called the Antonine plague also known as Galen's plague, that lasted from AD 162-180 and killed an estimated 10% of population of the Roman Empire. The plague was named after the then Emperor of Rome (not a great thing to be remembered for) and was thought to be caused by smallpox or possibly measles and was descried by the Greek born physician named Galen. In general, there is no systematic accounting for causes of death for individuals or groups of people anciently (3).

Likewise, the Christian church, though recording a person's death, did not record cause of death. It has been suggested that the church was more concerned about the fate of the soul than the fate of the body thus no collection of death information was made (1). That changed in the year 1532 in the Church of England parishes in and around London.

The first known attempts to identify, tabulate, and report causes of death were known

as Bills of Mortality that first appeared in 1532 with the number of deaths documented initially and sporadically. In 1603 this changed to weekly reporting (1). In 1629, during the reign of King James I, cause of death was added to the weekly report and thus became the first systematic data collection of why we die. Data for the Bills was collected only for persons buried in parish churches in the London area initially and later expanded to other areas (4). The guild known as the Worshipful Company of Parish Clerks were charged with collecting this information and submitting it to local authorities. When a person died the sexton, who was responsible for preparing the grave, alerted the searchers, usually pairs of older women paid by the parish to determine the cause of death (Boyce N. Bills of mortality. Tracking disease in early London. Lancet



2020;395:1186-1187). They were had no particular medical training but picked up the skills while on the job. Information had to be collected and submitted by 6 pm on a Tuesday. The data was collated and printed on the printing presses owned by the Company of Parish Clerks, and by Thursday copies were made available to the King and Privy Council, London Mayor and Alderman, and then made available to the public. You could buy an annual subscription in 1631 for 4 shillings a year. Figure 1 (4) is an example of a Bill of Mortality for the year 1665. It provides the number of people who had died by location of burial and causes of death. As an arthritis specialist, I take special note that 27 people were reported to have died of gout and

sciatica in 1665 (must have been impressive cases of gout!). Also, look at the number of people in London area reported to have died of the plague that year (68,596). London was hit by a major episode of plague in 1665 -1666 and we know exactly how many members in good standing of the Church of England in the London area died of the plague and other causes. If you were a dissenter from the church, or Jewish, or Roman Catholic, or some other faith, and thus not buried in a Church of England sanctioned parish graveyard your cause of death was not recorded. Bills of Mortality were not collected for the whole realm as noted but it was a start. The Bills ceased being collected and reported in 1858 because something better was happening.

One person caught the vision of what could be gained from the information contained in the Bills of Mortality. John Graunt, a London haberdasher or clothing merchant, published

Natural and Political Observations Made on the Bills of Mortality in 1662. He systematically went through the information contained in the Bills and may be considered the first epidemiologist (6). He reported among other things that one-third of children died before the age of five, documented the rise of rickets (bone disease due to vitamin D deficiency) in the London area, and described the impact of the plague. It became the talk of London when it was published, and he was inducted into the newly formed Royal Society. Unfortunately, he did not contribute anything further to the field, was later ostracized due to his conversion to Roman Catholicism, and his haberdashery burned down in 1666 during the Great Fire of London. He died a pauper in 1674. But the

OBSERVATIONS

Mentioned in a following INDEX,

and made upon the

Bills of Mortality.

By JOHN GRAUNT.

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possibilities of vital statistics on death had been demonstrated.

So why did it take so long in the course of human history to document causes of death? My own experience in medicine has taught me that humans rarely collect information until the information can be put to some practical use. For example, methods for assessing the efficacy

of medications to treat rheumatoid arthritis were only developed in response to the development of highly effective medications used to treat the disease. What was the motivation for the Bills of Mortality? It was likely over concern for the plague. The Bills of Mortality documented location of the cases of plague by parish and thus is it possible that they helped the living steer clear of those locations. The 1629 order from the Court of King James for collecting all causes of death is less clear. Maybe someone was simply curious. The understanding of disease processes and methods for intervention that developed in the late 19th and early 20th centuries likely was the driving force behind the detailed death certification that began in the middle of the 19th century and continues today.

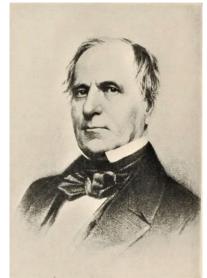
The next milestone in death reporting occurred again in England in 1838 with the appointment of William Farr as Compiler of Abstracts to the General Register Office, an office he held for 40 years. He was responsible for systematizing the collection of mortality data and using the data to understand disease processes. The power of such dry but important information was then used to understand the epidemiology of cholera as it occurred in England, a truly landmark breakthrough in public health. His other important contribution to the science of death was to provide for the International Statistical Congress in 1853 a list of the causes of death to be used for standardizing mortality worldwide. His classification system included 139 causes of the then understood ways of dying. The list included conditions such teething which in the 21st century we know is not fatal but may result in parents wishing they were dead due to lack of sleep from a crying child keeping them up at night. "Teething" deaths likely occurred when the child was being weaned from mothers' milk and unpasteurized animal milk was being introduced to the diet and thus the death was an infectious one. I am certain that 100 years from now someone will look back at our misattributions and shake their heads in wonder.

In 1891 this process of categorizing disease was taken to the next step. Jacques Bertillon, Chief of Statistical Services of the City of Paris chaired a committee of the International Statistical Institute and under his direction the first International Disease Classification (ICD) was born with the first ICD being published in 1893. It documented not just causes of death but disease in general.

From this first ICD in 1893 we currently have the distant grandchild of that effort in the overly complex International Statistical Classification of Disease and Related Health Problems version 11 aka ICD-11 that health care providers and insurance companies use for coding of illness and payment to health care systems and providers use to code for death. It's 17,000 coded diseases and causes of dying and 120,000 ways of coding those possibilities might make Farr turn over in his grave at Bromley Common in Southeast London, but we now know with exacting detail why we get ill and why we die.

In the New World, the English colonists likely brought the Bills of Mortality experience

with them. In 1632 the Virginia Grand Assembly passed a law requiring parishes to keep records of christenings, marriages, and burials. In 1639 the Massachusetts Bay Colony did something similar but with two important differences; The records would be kept by a government official and not the clergy, and the record would be of events i.e., births, marriages, and deaths and not just ceremonies. The next major step forward also occurred again in Massachusetts 200 years later by Lemuel Shattuck (Figure 3), a member of the American Antiquarian Society which was devoted to all things regarding American History, and a future founding



member of the New England Historic Genealogical Society. Somehow, he was able to retire at age 45 and founded yet another important society, the American Statistical Association, in 1839. He realized as one interested in vital statistics and genealogy that a government sponsored effort was needed to record societies vital information. He was instrumental in passing a law in Massachusetts that enabled the state government to collect vital statistics including causes of death which became a model for other states. Of interest, Massachusetts was the first state to issue death certificates in the year 1841. Shattuck's crowning achievement was as Chair of the Massachusetts Sanitary Commission that issued a report in 1850 on the health of the state and included 50 recommendations for improving public health that are now standard components of American public health practice.

At about the same time, the American Medical Association (AMA) began to promote the need for national mortality statistics and in 1847 lobbied state legislatures to collect information on vital events. There was an attempt to use the national census that took place every 10 years to identify causes of death for individuals. This every 10 years death registry is known as the United States Census Mortality Schedules and collected information of people who died between June 1st in the year prior to the census and ended May 31st in the year of the census. This national effort to collected causes of death happened from 1850 through 1900 (10). In 6 states, Colorado, Florida, Nebraska, New Mexico, North Dakota, and South Dakota a federal census took place in 1885 as well and included mortality schedules. We do not have the 1890 mortality schedules as these were destroyed along with most of the 1890 census population data during a fire in the US Commerce Department Building that occurred in January 1921. Actually, fire destroyed 25% of the forms, water used to put out the fire damaged another 37%, and the remaining 38% undamaged records from the 1890 census were subsequently destroyed by the government in 1934 for some reason. The 1900 mortality schedules were ordered destroyed by congress with the exception that the Minnesota mortality schedules somehow survived and have been published by the Minnesota Historical Society. We will discuss the nuts and bolts of using and accessing mortality schedules in more detail in the next section.

Outside of the federal attempts to collect death information, individual states and counties become involved in collecting vital statistics including death information on an ongoing basis. The first state to do so as noted was Massachusetts in 1841 and the last state to do so was New Mexico in 1920.

Many of the states/counties were collecting information in the form of death registries before the states actually mandated death data collection. Below is a death registration for

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King County, Washington in 1893. The state of Washington mandated certification did not occur until 1907. The information contained in the county registry is fantastic! Includes name, date of death, age, sex, race, marital status, place of death, cause of death, place of birth, location of residence, occupation, name of parents and place of birth of parents and name of the informant! A family history gold mine! I have had a chance to review registries from other states at this time period and the data collection is very similar and mirrors the data collected in the mortality schedules including cause of death.

In 1902 the US Bureau of the
Census was made a permanent agency
of the federal government and an
effort was undertaken to collect death
vital statistics at a national level. A
few years before, the Bureau issued a
recommended national death
reporting form and thus was born the
US Standard Certificate of Death.
Figure 4 is an example of the version
of the 1900 certificate. It is for Moroni
Pratt (note his famous father) who
died in 1913 and in general includes

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information basically similar to the current version of the US Standard Death Certificate but

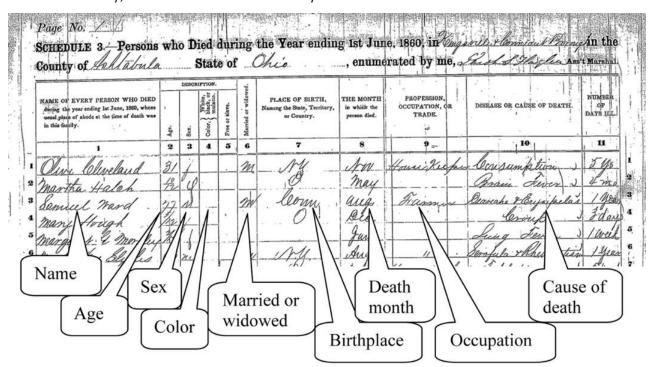
with a less detail as will be seen. If you are Gen Z you may not be able to read Moroni's certificate since it is in cursive writing, but your boomer grandparent will be able to interpret it for you. The modern death certificate in the US tries to capture the sequence of events leading to death and provide a more comprehensive picture of our graduation from mortality.

Section 2: Additional Information on US Mortality Schedules, Death Registries, and Death Certificates and How to Access the Data

First, I want to give you an excellent site that provides a glossary of medical terms used in the 18th and 19th century as it will help you understand why your ancestor died. It can be accessed at: https://www.thornber.net/medicine/html/medgloss.html

Mortality Schedules

The US mortality schedules are limited in scope and likely underestimate actual deaths, but they provide an interesting family history and medical picture of the US for us. The 1850 and 1860 mortality schedules included name of deceased, age at death, sex, color, status (free or enslaved), marital status, birthplace, month of death, occupation, cause of death or disease, and number of days ill. With the passage of the 13th amendment in December 1865 which abolished slavery, future schedules of mortality did not include free or enslaved information



nor were the number of days ill collected. Whether mother or father were foreign born and house number on the general census was added to 1870 schedules onward.

An example of the mortality schedule from 1850-1860 from FamilySearch Wiki demonstrates the information available to the family historian and is seen in figure 4. Not labeled but important from a medical standpoint is the days ill on the far-right column. Also note the enumerator or collector is designated as an assistant marshal and this is seen in all the mortality schedules I have reviewed. The assistant marshal was responsible for the collecting all census data at this period of time.

Below is an example of the mortality schedule from 1870 onward. It is a mortality schedule entry for Jun 1, 1869 to May 31, 1870 for Springfield, Henry County, Missouri.

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umn of Schedule 1.	Name of every person who died during the year ending June 1, 1870, whose place of abode at the time of death was in this family.	Age last birth-day. If under one year, give months in fractions, as in-	Sex-Males (M.), Females (F.)	Color-White (W.), Black (B.), Mulatto (M.), Chdnese (Ch.), Indian (I.)	Married (M.) or Widowed	Place of Eirth, naming the State or Territory of the U. S., or the country, if of foreign birth.	Father of foreign birth.	Mother of foreign birth.	The Month in which the person died.	Profession, Occupation, or Trade.	Disease or Cause of Death,
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Mortality schedule data is listed by state and county that existed at the time of the data collection. It is death registration for 7 persons including Samuel Boyd, possibly one of my distant relatives. He is designated as **family 322** from the household number noted in the 1870 census record. The household number can be very helpful if you want to confirm that this is your relative as you can go to the actual census record for and look up the household and see who is there. Beginning with the 1850 census every member of the household was listed while prior census data only included head of house. Sam Boyd's age at death, sex, race, place of

birth, and the month that he died (January 1870) as well as the cause are all listed. He died of consumption or tuberculosis, a common cause of death in the 19th century. Sam O'Brien , the assistant marshal omitted listing Sam Boyd's occupation unfortunately and thus are missing a key element in understanding Sam Boyd's life. Beginning with the 1870 mortality schedules days ill is no longer collected. Question as to whether either of his parents were foreign born is added. Do note that little William Barrett from household 355 died at one year of age of "teething", one of Farr's 139 recognized causes of death.

Mortality schedules have been suggested useful on various sites to explore possible downstream disease risk. From my perspective, they are marginally useful due to time limited data collection and definitive disease diagnosis. We will discuss disease terms both old and new that might help the family historian later. We will also discuss diseases to look out for in mortality schedules, in death registries, and death certificates.

Death Registries

Death registries were kept by the states and counties although I do not yet understand how pervasive an effort was placed in collecting the data nationwide. The machinery for collecting the death information seems to have grown out of the mortality schedules that started in 1850 and it appears the local governments continued to collect much of the same information collected during the mortality schedule activities including cause of death. These registries are more likely to provide useful information to construct a family health profile than the mortality schedules since they are collected on an ongoing basis and more likely to capture a consistent health picture. They still suffer from useful diagnoses due to the level of 19th century medical sophistication.

Death Certificates

Currently death recording in the US is under state jurisdiction and then sent to the CDCs

National Center for Health Statistics. Most if not all states have adopted the standard US

Standard Death Certificate version 2003 that will we review. Death certificates are certified i.e.

can be used for legal purposes to settle probate etc. or informational for use by family

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cause of death which was listed as acute coronary thrombosis or heart attack. The certifier can comment on other medical information that can be very important to the family historian (me in this case) trying to develop a family health portrait, but it is not provided for my grandfather. The cause of death is a superficial description of why my grandfather died. It lacks the important sequence we need to fully understand his graduation from mortality. I know that right before he died, he fractured his ankle while building a new church meeting house and was thus immobile and likely developed a DVT that then sent a large pulmonary embolus to his lungs as the cause of death, but I am looking in hindsight as a physician.

The other important issue for the family historian is who is providing the information i.e. the **informant**. In this case it was his son so the demographic information is likely good. If the informant is a grandchild or nephew (second degree relative) the information might be less than perfect. They might not know date of birth or location of birth or even correct name

especially if the person used their middle name all their life. So, make sure you do not count on the death certificate as the final word on important dates.

To the right is another issue you may run into when reviewing death certificates. It is the death certificate for Harry Houdini the famous escape artist. His cause of death is a bit better described i.e. acute peritonitis as a result of a ruptured appendix. But what are all the numbers on the death certificate? These are the ICD codes for disease that we discussed earlier and in this care are from ICD 3 (1920) listing his diagnoses:

90 is the code for heart disease (not written on the certificate), 117 is appendicitis,

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3 5	EX	4 Color or Race	5 Single, Married, Widowed or Divorced (Write the word)	(Month, day and year) Oct. 3]	,1926
- 1	Male	White	Married	IT HEREBY CERTIFY, That of strengt	THE RESERVE AND ADDRESS OF THE
Sa	If married.	widowed or divorced		900 25 ,026 . Oct	31.1026
	(or) W	FE of Beatri	ice Rahner	that I last saw Marilys on Det.	31 12/26
6 D	ATE OF BI	RTH Ang	11 6, 1874.	that death occurred on the date stated	JO P.
	CE	Years Months	Days If LESS then	The CAUSE OF DEATH' was as follows	
97	52		1 day bes	there here	ourtes.
	52	6	25 OR min.	(Dook them	ciel
	OCCUPATIO	ON OF DECEASED		(-	.7
	(a) Trade,	profession or Acto	r. & Legtudrar	(duration)	11-15
			ninina mapa ma	CONTRIBUTORY Red terred	
	business, o	l sature of industry, r establishment in duyed (or employer)		(Begondary) lightles	100
		f employer.	90	. La duration)yra.	
91	state or oo	CE (city or town)	Appleton, Wiscons	18 When was disease contracted	hontre
T	10 NAME	OF FATHER SA	amuel Mayer	Did an operation precede destat. D De	to of 1.0/25
1	11 BIRTHI		man amy or	Was there an autopay?	
2	OF FAT	THER (city or town) or country)	Unknown	What test confirmed diagnosist . Thors	alram.
EN.				3 (Send) Chas. S. Jan	actor u
N N	OF MO		ilia Steiner	Moul 192 LANGE 10 Pe	lea Office
-	13 BIRTH	PLACE		*State the Disease Causing Death, or in	deaths from Violes
	OF MO	THER (city or town)	Unknown	"State the Disease Causing Death, or in Causes, state (1) Means and Nature of Injury, cidental, Suicidal, or Homicidal.	and (2) whother A
		or country/		(See reverse side for further instructions.)	0015
14	Informant	Theodore Hay		19 PLACE OF BURIAL, CREMATION, OR REMOVAL	Date of Buria
	(Address)	537 B. 21	t Street Brookle		10/1/2619
15	Filed		CONTRACTOR OF THE SAME AND ADDRESS OF THE SAME ADDRESS OF THE SAME AND ADDRESS	20 UNDERTAKER	Address
100	Filed		Registrar.	William R. Hamilton Co.	Detroit

126 is peritonitis. The ruptured appendix and peritonitis are not likely useful information for a family health portrait **BUT** the fact that he is said to have heart disease at the tender age of 52 might have downstream implications for his descendants. You can look up the ICD numbers from all versions of the ICD based on when the death certificate was issued at this excellent website: http://www.wolfbane.com/icd/

Finally let's look at a current 2003 version of the death certificate and discuss pearls and pitfalls. A full copy of the current death certificate is after the references for you to review. All standard demographic information are listed including surviving spouse name. A question about the role of tobacco in the death is asked as is information on possible pregnancy related death. More information is also asked about relationship to injury, the education of the decedent, and ethnicity and race.

The cause of death has specific instructions on how to be filled out and should follow a specific sequence which many medical articles lament is not followed. The mechanism of death should be followed by the sequential conditions leading up to cause death and should

look something like this: ruptured myocardium (heart wall) as the mechanism of death, as a result of myocardial infarction (heart attack), the cause of the ruptured heart wall, as a result of coronary artery disease (hardening of the arteries supplying the heart) the predisposing issue that led to the heart attack.

For the family historian trying to develop a family health portrait the actual terminal event may be less important than the contributing factors that lead up to the death. The heart attack and long-standing coronary artery disease as well as the information in **other significant conditions** listed separately on the death certificate will be most helpful. Death certificates are probably the most helpful piece of information for the family historian to become a medical genealogist only second to getting such information from a living relative although I have found that many of us don't know that information even for first degree relatives.

How to Access Mortality Schedules, Death Registries, and Death Certificates

Mortality Schedules

All the mortality schedule data was offered back to the states in 1918-1919 by the Bureau of the Census and some took the information, and some did not. For the states that were uninterested, the forms were placed in the library of the Daughters of the American Revolution in Washington, D.C. The US Census Bureau has a 5-page PDF of where the actual mortality schedule data resides and if any exists. For example, some current states such as Colorado were not included in the census and thus mortality schedules until 1870 due to the fact Colorado was not a US territory until 1861 and a state in 1876. Here is the link for the Bureau of Census that tells you basic information on the mortality schedules.

https://www.census.gov/history/www/genealogy/other_resources/mortality_schedules.html

Ancestry.com apparently has the most complete online collection of mortality data and a smaller listing is available on FamilySearch.org. I note that Florida has made available all of its original mortality data online and is available for those interested at:

https://www.floridamemory.com/discover/historical_records/mortality-schedules/
Indiana and other states have done the same so look up mortality schedule and state you are interested in to see if an online collection exists. With time, more of the data will be digitized

and available to the interested family historian. Remember that to be listed, the person you are looking for had to die in a one-year window prior to the June census.

Accessing state and county death registries can be challenging but doable. Listings can be found on all major genealogy sites including FamilySearch and a reasonable place to start is on FamilySearch Wiki on death records and you may just get lucky:

https://www.familysearch.org/en/wiki/How to Find United States Death Records

I do note that the digitized death records on FamilySearch DO NOT INCLUDE CAUSE OF DEATH which of course I think is a major lost opportunity. You can find it though if you go to the original document attached to the digitized document. Ancestry.com also has a searchable database of death records that includes registries and again cause of death is not included on the digitized result record. I also found what looks like to be a regularly updated listing of death indexes in the USA that included fee

based and free sites at: https://www.germanroots.com/deathrecords.html.

Death certificates

Many of the same sources for mortality schedules and death registries will get you to information on death certificates. Some states restrict access while others consider them public information. Some states will release a copy to you for a fee. Most first-degree relatives will have a copy of the death certificate for legal purposes of settling the estate. I am a strong advocate for placing death certificates on your genealogical site of choice connected to your relatives to make it easy for descendants to create a family health portrait. I do so whenever I can find one. There are certainly cases where the cause of death might be a sensitive issue and there may be reluctance to put a death certificate on a public site. As will be seen, to create a reasonable family health portrait and determine risk of disease one needs medial information on at least parents, siblings, aunts, uncles and grandparents but the more the merrier.

Section 3: Common Genetically Associated Illnesses and How to Create You Own Medical Pedigree and Calculate Disease Risk

Let's review some of the common illness in which family history is important. If there is concern about an increased risk of any of these diseases, you should consult your care provider to discuss the concern. Link to the CDC site and information on these illnesses is located at: https://www.cdc.gov/genomics/famhistory/famhist_chronic_disease.htm

Heart and Blood Vessel Disease

This is a big one. It accounts for 1 in 5 deaths in the US every year. Determining risk of heart disease and blood vessel disease is dependent on it being present through several generations and is useful to look for on death records. The history could be listed as heart attack (myocardial infarction, MI, coronary thrombosis coronary artery disease), heart failure (dropsy is an old term for heart failure), cardiovascular, arteriosclerosis, stroke (cerebrovascular accident, CVA, or apoplexy old term for stroke), or hypertension. Risk factors for developing heart and vascular disease include besides family history, smoking, hypertension or high blood pressure, being overweight, high cholesterol, heavy alcohol use, and diabetes. Modifying these risk factors will reduce your risk of developing heart and blood vessel disease.

One of the above terms will show up on death records and if it shows up frequently and early i.e. earlier than age 60 it should definitely be on your radar and talk to your health care provider about what you find.

Breast and Ovarian Cancer

A woman with a family history of breast or ovarian cancer especially in a parent, sibling or child is at an increased risk of developing one of these cancers. If you have had one of these cancers other family members need to know. The presence of these cancers might require starting screening at an earlier age than usual and may trigger a genetic test for BRCA1 or BRCA2 genes. The things you can do to lower your risk of breast cancer include maintaining a healthy weight, exercise on a regular basis, avoid alcohol, and have a discussion with your

health care provider about hormone therapy if you are on or contemplating use. No know way to modify risk for ovarian cancer at the current time. Cancer of the breast was first appeared a distinct diagnosis on ICD2 in 1909. Before that likely lumped into tumor or cancer. Cancer of female genital organs also show up in ICD2 but the ovary specifically appears in ICD 6 in 1948.

Colon Cancer

Having several family members with colon cancer especially if colon cancer was diagnosed before age 50 years of age are at an increased risk of developing colon cancer. If so, screening needs to start at age 40 rather than 45 and have more frequent screening at the recommendation of your health provider. Screening should be colonoscopy rather than other methods to look for cancer cells that are advertised on TV

Lynch syndrome is hereditary form of colon cancer and people with the Lynch syndrome genetic abnormality are at increased risk of not only colon, but also uterine, stomach, liver, kidney, and brain tumors. Look out for cancers in ancestors at an early age but also living relatives.

Cancer of the intestines and other abdominal organs shows up in ICD 2 of 1909 but cancer of the large intestine first appears in ICD 6 in 1948.

Diabetes

Diabetes was able to be diagnosed at least as far back as the 1600's. Physicians would note the symptoms (frequent urination and thirst) and taste the urine for sweetness (yikes). There are four different versions of diabetes. **Prediabetes** (those at risk for developing type 2 diabetes) affects around 96 million people in the US. People with prediabetes have a high risk for the disease but have not yet developed the disease and modification of risk factors might prevent every developing diabetes. **Type 1 diabetes** is autoimmune disease where the immune system attacks the pancreas and the insulin producing cells are destroyed and can no longer produce sufficient insulin to control blood sugar. Type 1 diabetes requires insulin therapy. It affects approximately 3-5 million people in the US. The majority of the 37 million people with diabetes have **Type 2 diabetes**. The pancreas still produces some insulin but due to insulin

resistance it does not meet the body's insulin needs. Finally, a transient form of diabetes can occur during pregnancy called **gestational diabetes**. Having gestational diabetes increases your risk of Type 2 diabetes in later life.

If you have a parent or sibling with type 2 diabetes your risk is high for developing this form of diabetes. Ways to help prevent Type 2 diabetes include maintaining a healthy weight, focus on a healthy diet (less processed foods, sweets, starchy vegetables, fast foods, sweetened drinks etc.), exercise, and regular check up with your health care provider. Monitoring the hemoglobin A1c level can also be helpful.

Look for diabetes or diabetes mellitus on death records or in significant medical condition on death certificates.

Osteoporosis

Osteoporosis, or weakening of the bones, affects 20% of women and 5% of men over age 50. It can be detected with an X-ray test called a DEXA and screening generally starts at age 65 for women or earlier if there a family history of osteoporosis/fracture. Ways to prevent osteoporosis include eating healthy that include calcium containing foods or a supplement (1000 mg) and vitamin D supplement of at least 1000 u daily. Also, avoid tobacco and alcohol and participate in weight bearing exercise on a regular basis. Use of medications like prednisone or having a chronic inflammatory disease like rheumatoid arthritis also contribute to the risk of osteoporosis.

Osteoporosis is a more recent medical term and first shows up in ICD 8 in 1965. The risk of osteoporosis is associated with the condition in a woman's close female relatives so one does not have to look far back in the records for the diagnosis or for fracture as a potential cause of death in an older female ancestor.

Hemochromatosis

Finally, a disease called hemochromatosis has a strong genetic link. It is found in 1 out of every 300 people of northern European descent (blame the Celts). It is a disease in which the body does not cycle iron properly and it accumulates in the body especially in the heart, liver pancreas, and joints. It can also affect the thyroid gland and even the testis. In untreated cases the skin may take on a bronze color. It can also lead to liver cancer in some affected people. Symptoms my first show up in men in their 40s-50s and women after menopause. The disease can cause heart failure, liver damage or cirrhosis, osteoarthritis especially in unusual joints, and diabetes. Look for multiple family members with diabetes, heart or liver disease on death records. It can be diagnosed with simple blood tests and can be treated by scheduled removal of blood from the body to remove excess iron.

Hemochromatosis is a recent term so as noted look for multiple family members with the above noted conditions and possibly more than one of these conditions in one ancestor. People with hemochromatosis should let close relative know about the diagnosis.

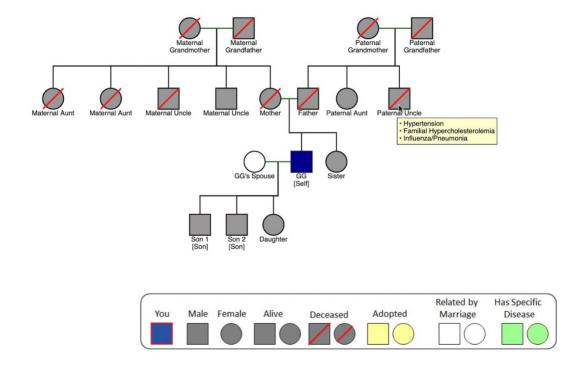
Creating your own medial portrait

The CDC has a fascinating website that include a program to create a family medical portrait that generates both a chart with important family history that you can share with your health provider and your family members and a medial pedigree that gives visual representation of your family's health. You can find it at and will need to cut and paste this address into your browser.

http://kahuna.clayton.edu/jqu/FHH/html/index.html

It also generates a risk profile for some of the diseases we have covered. You save the file to your computer in an XML format (not in the cloud) and you can change the file as you find more information. You apparently can add any number of ancestors. You start the pedigree with you, siblings, parents, grandparents, uncles and aunts. Below is an example of what you can do using a made-up family. If you have the information in front of you can count on 30 minutes to 1 hour or so to enter the data and generate the reports.

Example of a medical pedigree generated

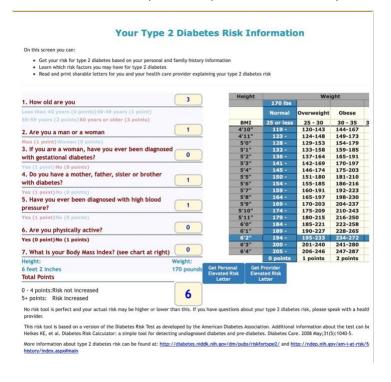


You can put the mouse arrow on anyone in the pedigree and their health issues are shown as noted for the paternal uncle. It also generates a family health table, a portion of which is shown below, and can be printed and provided to your health care provider or shared with other family members.



Finally, it will assess your risk of certain illnesses and for diabetes gives you a risk score as noted below. The more ancestors you add, the more complete the picture will be and you

and the program may recognize some consistent illness or uncover unusual diseases that run through several generations that might suggest rare conditions like Lynch syndrome that will need to be discussed with your care provider.



Suggestions on how to gather important family health information:

- 1. Include important illness in personal and family member life histories
- 2. Discuss important family illness at family reunions if comfortable doing so and discuss the reasoning behind it
- 3. Lobby major family history sights for digitizing important health information from causes of death from mortality schedules, death registries, and death certificates

To wrap it up, I hope that our discussion has been useful to you and will encourage you to be more interested in adding death and medical information to your family history as such information can truly benefit the living and the dead!

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- 14. https://www.thornber.net/medicine/html/medgloss.html website for old medical terms
- 15. http://www.cdc.gov/nchs/howto/w2w/w2welcom.htm helpful is you want a copy of death certificate that is not online
- 16. https://www.cdc.gov/genomics/famhistory/famhist_chronic_disease.htm website discussing important familial diseases
- 17. http://kahuna.clayton.edu/jqu/FHH/html/index.html website to develop your own family history portrait

ILS STANDARD CERTIFICATE OF DEATH

LOC	CAL FILE NO.	U.S. STANDARD CER		TATE FILE NO.								
	DECEDENT'S LEGAL NAME (Include Al	KA's if any) (First, Middle, Last)	2. SEX 3. SOCIAL SECUI									
	4a. AGE-Last Birthday (Years) 4b. UNDER 1 YEA		IRTH (Mo/Day/Yr) 6. BIRTHPLACE (City and St	tate or Foreign Country)								
	7a. RESIDENCE-STATE	Hours Minutes 7b. COUNTY	7c. CITY OR TOWN									
	74. NEOIDENOE-OTATE	75. COONTY	76. GITT GICTOWN									
	7d. STREET AND NUMBER			g. INSIDE CITY LIMITS?								
	8. EVER IN US ARMED FORCES? 9. MARITAL STATUS AT TIME OF DEATH 10. SURVIVING SPOUSE'S NAME (If wife, give name prior to first ma											
d By:	11. FATHER'S NAME (First, Middle, Last)	TO FIRST MARRIAGE (First, Middle, Last)										
/ Verifie	13a. INFORMANT'S NAME 13	b. RELATIONSHIP TO DECEDENT	13c. MAILING ADDRESS (Street a	nd Number, City, State, Zip Code)								
pletec L DIRI	IF DEATH OCCURRED IN A HOSPITAL:	14. PLACE OF DEATH (Check only	one: see instructions) JRRED SOMEWHERE OTHER THAN A HOSP	PITAL:								
To Be Completed Verified FUNERAL DIRECTOR:	I Inpatient I Emergency Room/Outpatient I Dead on Arrival I Hospice facility I Nursing home/Long term care facility I Decedent's home I Other (Specify): 15. FACILITY NAME (If not institution, give street & number) I Hospice facility I Nursing home/Long term care facility I Decedent's home I Other (Specify): 16. CITY OR TOWN, STATE, AND ZIP CODE 17. COUNTY OF DEATH											
i i	18. METHOD OF DISPOSITION: Burial Cremation Donation Denomination Removal from State 19. PLACE OF DISPOSITION (Name of cemetery, crematory, other place)											
2	Other (Specify):	21. NAME AND COMPLE	TE ADDRESS OF FUNERAL FACILITY									
	22. SIGNATURE OF FUNERAL SERVICE L	ICENSEE OR OTHER AGENT		23. LICENSE NUMBER (Of Licensee)								
	ITEMS 24-28 MUST BE COMPLI	FTFD BY PFRSON 24. DATE	PRONOUNCED DEAD (Mo/Day/Yr)	25. TIME PRONOUNCED DEA								
	WHO PRONOUNCES OR CERT	IFIES DEATH	27. LICENSE NUMBER	DATE CONST (M. D. A.)								
	26. SIGNATURE OF PERSON PRONOUNC		27. LICENSE NUMBER	28. DATE SIGNED (Mo/Day/Yr)								
	 ACTUAL OR PRESUMED DATE OF DE (Mo/Day/Yr) (Spell Month) 	ATH 30. ACTUAL OR P	RESUMED TIME OF DEATH	31. WAS MEDICAL EXAMINER OR CORONER CONTACTED? [] Yes [] No								
	C.	AUSE OF DEATH (See instruction	ns and examples)	Approximate interval:								
	32. PART I. Enter the chain of events —diseases, injuries, or complications—that directly caused the death. DO NOT enter terminal events such as cardiac arrest, respiratory arrest, or ventricular fibrillation without showing the etiology. DO NOT ABBREVIATE. Enter only one cause on a line. Add additional lines if necessary. Onset to death											
	IMMEDIATE CAUSE (Final disease or condition> a.											
	resulting in death)	Due to (or as a conseque	nce of):									
	Sequentially list conditions, b if any, leading to the cause listed on line a. Enter the	Due to (or as a conseque	nce of):									
	UNDERLYING CAUSE c (disease or injury that	Due to (or as a conseque	ence of):									
	initiated the events resulting in death) LAST d											
	PART II. Enter other significant conditions c	ontributing to death but not resulting in the und	erlying cause given in PART I	33. WAS AN AUTOPSY PERFORMED?								
				34. WERE AUTOPSY FINDINGS AVAILABLE TO COMPLETE THE CAUSE OF DEATH? Yes No.								
ier.	35. DID TOBACCO USE CONTRIBUTE TO DEATH?	36. IF FEMALE: Not pregnant within past year	37. MANNER OF									
Completed B	☐ Yes ☐ Probably	Pregnant at time of death		ral								
CALC	□ No □ Unknown	Not pregnant, but pregnant within 42 da	ys of death	Could not be determined								
To Be Con MEDICAL		☐ Not pregnant, but pregnant 43 days to		Code not be accommed								
	38. DATE OF INJURY 39. TIME OF	Unknown if pregnant within the past year INJURY 40. PLACE OF INJURY (e.g.	ar ., Decedent's home; construction site; restauran	t; wooded area) 41. INJURY AT WORK?								
	(Mo/Day/Yr) (Spell Month)			☐ Yes ☐ No								
	42. LOCATION OF INJURY: State:	City or Town:		1								
	Street & Number: 43. DESCRIBE HOW INJURY OCCURRED	:	Apartment No.:	Zip Code: 44. IF TRANSPORTATION INJURY, SPECIFY:								
				☐ Driver/Operator ☐ Passenger ☐ Pedestrian ☐ Pedestrian								
	45. CERTIFIER (Check only one):											
	☐ Certifying physician-To the best of my knowledge, death occurred due to the cause(s) and manner stated. ☐ Pronouncing & Certifying physician-To the best of my knowledge, death occurred at the time, date, and place, and due to the cause(s) and manner stated. ☐ Medical Examiner/Coroner-On the basis of examination, and/or investigation, in my opinion, death occurred at the time, date, and place, and due to the cause(s) and manner stated.											
	Signature of certifier:	s or examination, and/or investigation, in my of	illion, death occurred at the time, date, and place	se, and due to the cause(s) and manner stated.								
	46. NAME, ADDRESS, AND ZIP CODE OF	PERSON COMPLETING CAUSE OF DEATH	(Item 32)									
	47. TITLE OF CERTIFIER 48. LICENSE	NUMBER 49. DATE CERTIFII	ED (Mo/Day/Yr) 50	0. FOR REGISTRAR ONLY- DATE FILED (Mo/Day/Yr)								
	51. DECEDENT'S EDUCATION-Check the											
	that best describes the highest degree or lev school completed at the time of death.		cedent is decedent consine "No" box if	 DECEDENT'S RACE (Check one or more races to indicate what the decedent considered himself or herself to be) 								
	8th grade or less	decedent is not Spanish/Hispanic/L	atino. White Black or Africar	White Black or African American D American Indian or Alaska Native								
	9th - 12th grade; no diplomaHigh school graduate or GED completed	No, not Spanish/Hispanic/Latino	(Name of the e ☐ Asian Indian	nrolled or principal tribe)								
Completed By: RAL DIRECTOR	High school graduate or GED completedSome college credit, but no degree	Yes, Mexican, Mexican American, C										
pletec	Associate degree (e.g., AA, AS)	Yes, Puerto Rican	Korean Vietnamese Other Asian (S	pecify)								
To Be Com FUNERAL	Bachelor's degree (e.g., BA, AB, BS)Master's degree (e.g., MA, MS, MEng,	Yes, Cuban Yes, other Spanish/Hispanic/Latino	☐ Native Hawaiia☐ Guamanian or ☐ Samoan	n Chamorro								
To Be FUNE	MEd, MSW, MBA)	Specify)	Other Pacific Is	slander (Specify)								
	 Doctorate (e.g., PhD, EdD) or Professional degree (e.g., MD, DDS, DVM, LLB, JD) 											
	54. DECEDENT'S USUAL OCCUPATION (Indicate type of work done during most of work	ng life. DO NOT USE RETIRED).									
	·	Indicate type of work done during most of work	ng life. DO NOT USE RETIRED).									