Legislative Budget and Finance Committee

A Report in Response to HR 1087 of 2020
COVID-19 Death Reporting

Report Comments by Stephen Fickes, Project Manager
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Good morning. Mr. Chairman and members of the Committee, it is a pleasure to be here today to discuss the results of our study pursuant to House Resolution 1087 of 2020. Before I begin with my overview this morning, I would like to provide additional context about House Resolution 1087 and some of the challenges in completing this work.

The House of Representatives adopted HR 1087 unanimously on November 19, 2020. The resolution asked the Committee to review certain aspects of COVID-19 reporting by the Department of Health. Specifically, we were tasked with obtaining information on death reporting and testing. The resolution required a series of reports to be completed every 90 days and lasting until 90 days after the Governor's emergency declaration ended. By action of the General Assembly, that declaration has since ended.

Shortly after HR 1087 was adopted, the officers of the Committee met—and as is the customary practice—adopted study objectives in response to the resolution. This report focuses on the death reporting process in Pennsylvania, and specifically, deaths attributed to COVID-19.

You will note that this report carries with it a scope limitation. I will discuss the reasoning for this occurrence later, but it was necessary for us to issue the scope limitation because we could not obtain original source documentation from the department. Although we issued this scope limitation because of restrictions imposed upon our work, the report does provide important detail about death reporting and tabulating deaths attributed to COVID-19, which I will now briefly outline.

Pennsylvania, like other states, follows guidance from the federal government with how deaths are to be reported. The process itself, however, is a state responsibility, and is mandated by Pennsylvania's Vital Statistics Law. Death reporting involves a coordination between two primary parties: medical certifiers and funeral directors, each of which is responsible for reporting certain aspects about the decedent. Funeral directors report demographic details, such as age, sex, and address—while medical certifiers, which includes primarily physicians, but also coroners and medical examiners—report information about cause of death. From here, things begin to get more complex, so I will provide a high-level overview of the process.

A death is reported to DOH, which it refers to as the "death report." This report reaches the department by one of two ways, either using a paper form known as a certificate of death, or more recently, electronically, through a system known as the Electronic Death

Registration System, or EDRS. Prior to the COVID-19 pandemic, EDRS use was not mandated, and only approximately 15 percent of deaths were fully reported using the system. Significantly, in March of 2020, the department mandated that all deaths from COVID-19 be reported through the EDRS system.

The reasoning for this change was apparent. With the likelihood of deaths increasing from COVID-19 timely and accurate death reporting was critical. One of the benefits of EDRS is that it offers a more efficient reporting platform; consequently, mandating usage of the system for COVID-19 reporting made sense from a disease surveillance perspective. Prior to the pandemic, Pennsylvania was one of the slowest reporting states to the National Center for Health Statistics (NCHS), which is an agency within the CDC responsible for collecting death data and performing certain medical coding. After mandating usage of EDRS, Pennsylvania has improved the timeliness by which these records reach the NCHS. We found that for calendar year 2020 Pennsylvania tied the national average and the mandated reporting through EDRS likely contributed to this occurrence.

I mentioned earlier that the department receives data about cause of death. This is a confusing concept, but it is important for understanding how deaths attributed to COVID-19 are identified and tabulated. Cause of death consists of two parts on a death

record. Part 1 focuses on the three-part chain of events causing death: the immediate cause of death, the intermediate cause of death, and the underlying cause of death. While these three conditions are interconnected, ultimately the *underlying condition* is what started the death sequence.

Part II of the cause of death focuses on significant health conditions, known as comorbidities. These are conditions that contributed to death, but are not conditions that resulted in the underlying cause of death as listed in Part I. Both parts are reported by medical certifiers based on their medical training and judgment, but it is not a definitive conclusion about the death.

Cause of death information is used as the basis for reporting death counts from COVID-19. In accordance with CDC guidance, the department counts a COVID-19 death as one where COVID-19 or similar terminology is listed anywhere on Part I or Part II. As part of its death reporting guidance, DOH specifically states that if COVID-19 did not cause or contribute to a death, it should not be listed on the data reported to the department.

Because COVID-19 deaths are counted using the information in Part I or Part II, oftentimes there is confusion about whether a person died *with* or *from* COVID-19. From a disease surveillance perspective, and per CDC guidance, the distinction is less

important because whether a person's life was shortened by 15 minutes or 15 years, COVID-19 played a factor in the death, and thus, should be counted.

I will now turn to an overview of our final report section, which is also the one where we encountered the most difficulty. Our intent for this report was to review a random selection of death certificates of citizens whose deaths have been attributed to COVID-19 to ensure the deaths were properly, accurately, and consistently reported. There was good reason why we wanted to look at a sample. We heard from numerous stakeholders including, coroners and funeral directors, about problems with EDRS and with death reporting generally, as well as COVID-19 death reporting specifically. Similar information was also reported in several media outlets. Further, given Pennsylvania's poor prior performance in timely reporting to the NCHS, the sum of these factors weighed heavily in our desire to see source documentation.

The department denied our requests for information stating that the information was protected under the Vital Statistics Law (VSL). The department is correct that this information is generally protected; however, the law also provides exceptions where the department may share data. Two of these exceptions include for an "agency of government," and for "research purposes." The department's full position is contained in Appendix B, but on both these allowable exceptions, the department concluded we

could not be granted access to source documentation. Our counsel responded to the department with further analysis about the authority of this Committee and requested reconsideration, which is contained in Appendix C. Through negotiations with the department, we eventually were offered highly redacted, piece-meal information about COVID-19 deaths in Pennsylvania. As we remained in a legal impasse over the matter, we accepted the information to keep this project moving forward.

The information we received from the department was a data file containing 17,834 records, which the department stated were deaths attributed to COVID-19 during 2020. Included in this data was the department's internal classification of the death, which it had determined from the full review of the death record, as well as the NCHS medical coding for just the underlying cause of death as reported on Part I of the death certificate.

After review, we found that of the 17,834 deaths where DOH had assigned its internal classification as being attributed to COVID-19, in nearly 9 percent of those records, or 1,596 records, the NCHS had coded the underlying cause of death as something other than COVID-19. The most prevalent of the causes included diseases of the circulatory system, mental and behavioral health disorders, and diseases of the nervous system. There is a likely reason why discrepancy exists between the two data points. The

department's classification is based on a review of *all* Part I and Part II of the death record, whereas the data presented to us from the NCHS' review, was only considering the underlying cause of death from Part I. To be clear, we do not dispute the guidance issued by the CDC as to how to count COVID-19 deaths, and to the best of our knowledge, the department is following that guidance. If we had access to source documentation about these deaths, we would be able to further test the data and confirm this conclusion.

Which brings me to our recommendations. Our first recommendation is that the department needs to improve its data collection and presentation on its website. We tried to reconcile certain data, specifically long-term care facility deaths, and could not do so, because the data was incomplete or conflicted with other data sources. As an indication of its agreement with this recommendation, the Acting Health Secretary recently rescinded a reporting requirement for skilled nursing facilities that was at the root of this confusion. Instead, the department now will publish skilled nursing facility data that is reported to the federal government through the Centers for Medicare and Medicaid. Our second recommendation pertains to establishing a taskforce of stakeholders to monitor the accuracy of cause of death reporting in Pennsylvania, and our final recommendation is to the General Assembly and recommends that it should

consider amending the Vital Statistics Law to expressly grant legislative service agencies access to vital record information needed to conduct authorized research and studies.

In conclusion, we thank the department for its assistance in completing this report. The fact that they assisted us during a pandemic does not go unnoticed. Finally, I would like to thank several staff members who worked on this project, including Rebanta Mukherjee, Stevi Sprenkle, and our newest analyst joining the LBFC, Matt Thomas. At this time, I would be happy to answer any questions you may have.