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MEDICINE

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STANFORD HEALTH CARE & SCHOOL OF MEDICINE



TDS Connection

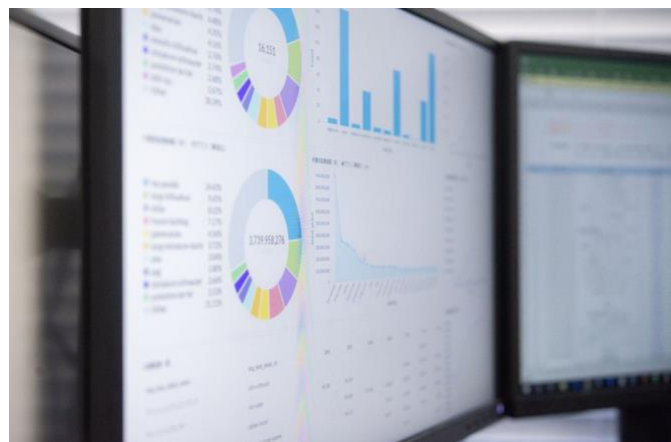
THE LATEST FOR TDS PARTNERS | October 2024

FEATURED STORY

Stanford's Data Collaboration to Enhance Insights on Mortality Trends

By the TDS Internal Communications Team

Keeping track of death rates is an important way to track the effectiveness of patient care. A cross-functional TDS collaboration team at Stanford Medicine is integrating decedent data from the California Department of Public Health (CDPH) into Epic, in an important project set to enrich Stanford Hospital death data manyfold, from 50,000 to an estimated 600,000. In this Q&A, **David Love**, Research Technology Strategy and Operations Lead for Technology and Digital Solutions, outlines what this collaboration has accomplished.

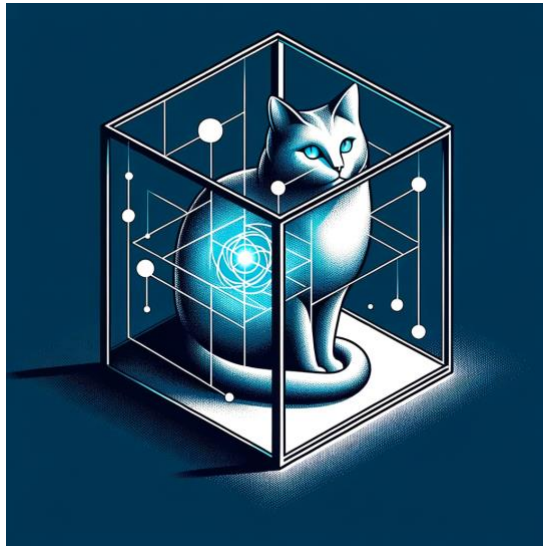


Q: Why is this project important and why now?

A: It seems self-evident that knowing whether a person is alive or dead is important. After all, that's what "vital status" means. We know when a patient death occurs in our hospitals, but don't always have reliable information if they pass away after leaving our facilities.

That's why I like to use Schrödinger's Cat as a model — we simply don't know whether someone is still alive or not since our last interaction with them. For both clinical and research purposes, we're looking for reasonable, affordable ways to improve our mortality information.

As for "why now"... I'm fond of the saying, "The best time to plant a tree was thirty years ago, the second best time is today." When I began this project, I learned that researchers, clinicians, and administrative offices had been seeking solutions for years, and had never gained traction. But until five years ago, there was no TDS. With TDS bridging the gap between the School and Hospital, we were finally able to bring together the many, many groups needed to make this happen.



*"We simply don't know whether someone is still alive or not since our last interaction with them."
DALL·E/SecureGPT image*

Q: How do decedent records impact various aspects of care, such as outreach and measure of quality?

A: For quality of care and reporting purposes, it's important to know how effective our care has been, especially reporting on 30-day mortality metrics. And anecdotally we've heard from different clinical units how traumatic it can be (on both sides of the connection) to reach out to someone with a vaccine reminder, a follow-up call, or a research study opportunity, only to discover that the patient has passed away.

Q: What was the source of our death data before this integration?

We had different answers for clinical use versus research use. On the clinical side, in addition to recording deaths occurring in our facilities, my understanding is that if someone (say a family member) reports a death to us, we will record that — at least "Fact of Death" if not "Date of Death" — after some corroboration. In some cases we also reach out to Experian to discern whether certain patients are deceased, but that is only for a portion of our records.

On the research side, we've augmented our Epic data with nationwide death information from the Social Security Administration's "Limited Access Death Master File" (LADMF) for many years. Unfortunately, that source has its shortcomings. The LADMF information is reliable when present, but delivers fewer records due to some regulatory changes about a decade ago; we now receive perhaps 100 new deaths per month from that source. In addition, it has enough strings attached that our researchers can find it unattractive to use. Finally, we can't push that data "upstream" into Epic; the hospitals cannot benefit from this research data source.

Q: How did we choose the California Public Use Death File?

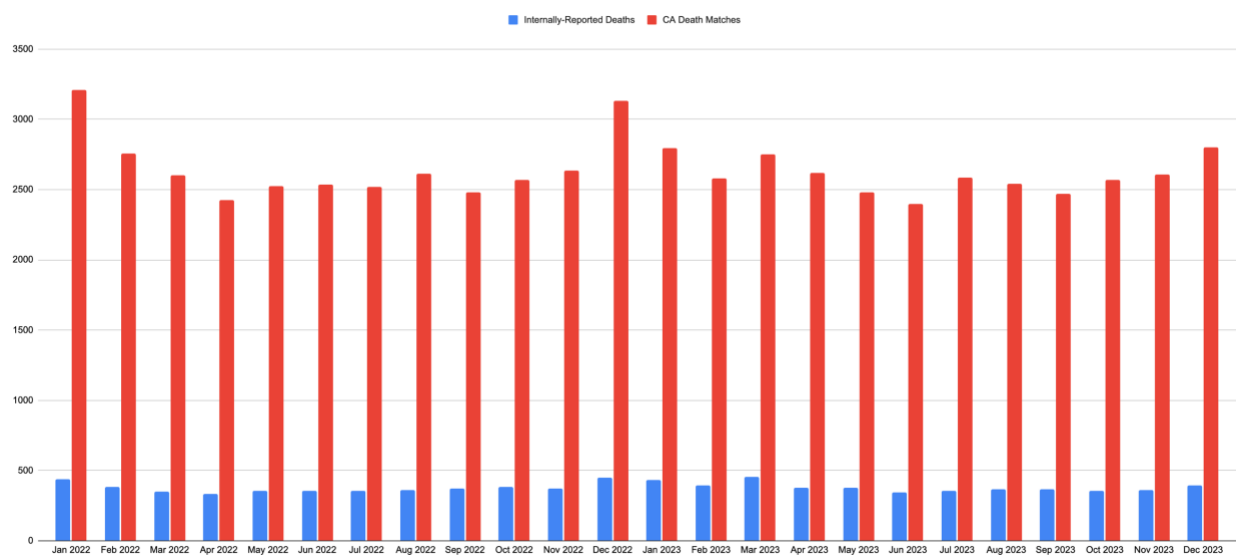
We looked at a variety of options to expand our sources, including state registries, commercial offerings, and national databanks. Coverage, recency, and cost varied wildly across these options. Thankfully, our Population Health folks introduced us to the University of California Health team and their leaders Mike Hogarth and Amy Sitapati, who had blazed the trail by obtaining the CA Public Use Death File for their use in 2016. UC Health had amazing success augmenting their own records with California death data (thousands of reliable matches) and had presented their work at Epic User Group Meetings. Their success and guidance gave us confidence that it would be a good source for us.

Q: Have you uncovered any trends in deaths with this additional information?

A: We've only just begun importing the California Death Data, so we don't have the complete set of data yet; we're hoping to have all data from 2001 onward matched to our Epic data by the end of October. But from what we've seen so far, this will be an extremely valuable new source of information.

We currently have about 50,000 patients with dates of death in our Epic, recording about 300-400 deaths per month in recent years.

Over this same period, CDPH data is yielding more than 2,500 potential new deaths per month, or more than six times the number we're currently recording. Of these "possibly decedent" matches, 97 percent of them are still deemed alive in our Epic data. Some of our records are noted as deceased without a date of death, so some of these potential matches would be providing a death date for a known decedent.



A visualization of the comparison between "about 400 internally-reported deaths per month" and "more than 2,500 California Death Data matches per month." Click the image for a larger view.

So if the quality of the match is high — which so far it appears to be — we may receive more than 600,000 new death records, far exceeding the 50,000 we currently have. Note that we’re considering these to be only “possibly decedent” until we validate the matches ourselves.

Q: As I understand it, we tracked causes of death already, but now we are getting much more data from the CDPH on top of our data. Do I have that right?

A: Sort of. And to clarify, this isn’t about “Cause of Death” (and in fact this new data doesn't include cause-of-death), this is solely about “Fact of Death” and “Date of Death.” In-hospital deaths are tracked by our own staff.

But the “much more data” you refer to is definitely true. We expect to greatly increase the number of deaths we are aware of. We aren’t yet trying to improve the depth of information about those deaths in this project. That being said, there is definite interest in getting “Multiple Causes of Death” information (the stuff “below the line” on death certificates), but that wasn’t within the scope of this effort.

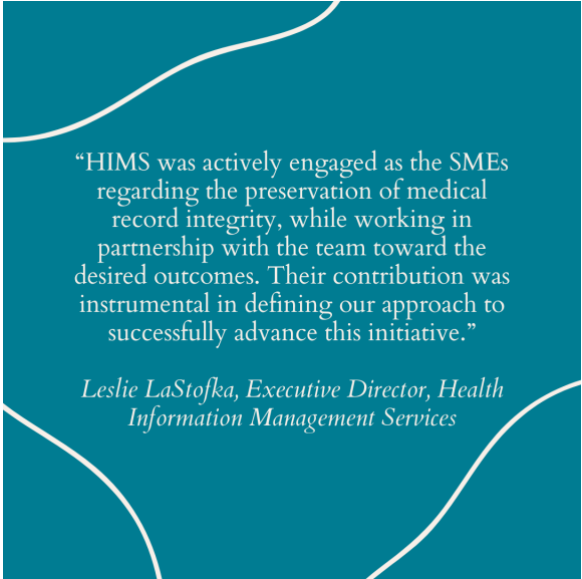
Q: What challenges are your team facing on this project?

A: We’ve been working on this project for a long time! For this California Death Data, the initial challenges were around the contract. It took a lot of back and forth to structure our “statement of intended use” so that both hospitals and the medical school could benefit; I can thank Philip Chen from our legal team for making that happen.

Once our internal negotiations were complete, it took months to navigate the Byzantine state process to apply for the data, which required Dr. Pfeffer’s personal involvement. And once our application was approved, we faced some technical hurdles with the encryption and delivery of the data, but RamKumar Chokkalingam and our Integration team overcame those.

As you might expect, there were lots of questions and opinions around governance, and TJ Davison from the PMO calmly gathered all parties within and outside TDS and guided us to agreement. We had numerous design sessions and test runs to tune and validate our import algorithm, with Natasha Brovarny from Revenue Cycle steadfastly leading that charge.

In addition, the sheer number of potential matches is an issue. We want to confirm that each proposed match truly is our patient before we officially move them from “possibly decedent” to “verified decedent.” Olga Grujic from Quality Reporting & Analytics built our confidence by validating close to 90% of a small sample with “a reasonable time investment,” but it was no small task. From our initial estimates, it is possible that validation could take up to five FTEs.



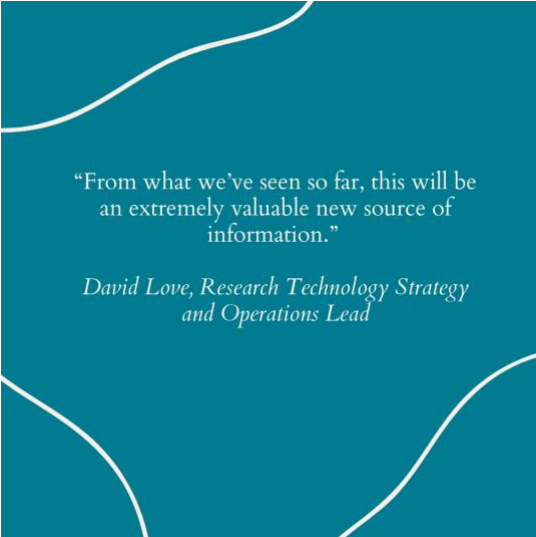
“HIMS was actively engaged as the SMEs regarding the preservation of medical record integrity, while working in partnership with the team toward the desired outcomes. Their contribution was instrumental in defining our approach to successfully advance this initiative.”

Leslie LaStofka, Executive Director, Health Information Management Services

Perhaps the last frustration occurred a week before our planned launch in May, when Epic informed us that they were deprecating the “externally reported death” data fields we’d planned to use. But we took a deep breath, made the necessary changes, and focused on a new launch date. At long last, we began importing California death data in July 2024.

Special Thanks and Recognition

The entire project wouldn’t have come to fruition without the dedication of many parts of Stanford Medicine: **Dr. Mike Pfeffer**, CIO; **Natasha Brovarny**, TDS Revenue Cycle; **Olga Grujic**, Quality Reporting & Analytics; **TJ Davison**, TDS PMO; **RamKumar Chokkalingam**, TDS Integration; and outside of Stanford, **Dr. Amy Sitapati** from UC Health.



“From what we’ve seen so far, this will be an extremely valuable new source of information.”

David Love, Research Technology Strategy and Operations Lead

We are also immensely grateful to the teams who have helped make it happen:

- TDS Research Technology
- TDS Revenue Cycle
- TDS Integration
- TDS Program Management Office (PMO)
- TDS Information Security
- SHC Leadership
- SHC/SU Legal & Privacy
- Quality Reporting & Analytics
- Hospital Information Management Services (HIMS)
- Decedent Affairs
- Enthusiastic Researchers
- UC Health