

Patients listed as alive in their electronic health records were actually deceased, according to data

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About 20% of patients whose medical records showed them as being alive with a serious illness were in fact deceased according to California data, leading to hundreds of unnecessary interactions such as appointment reminders, prescription refills and other kinds of wasteful outreach that strain resources and health care workers' time.

The data gap is due to California law that makes these full death data available only "for purposes of law enforcement or preventing fraud," according to a UCLA-lead research team. Even a real-time death database maintained by the National Association for Public Health Statistics and Information Services remains unavailable to [health organizations](#), they write.

The findings are published Dec. 4 in a *JAMA Internal Medicine* research letter.

The problem exists for nearly all California hospitals and in some other states, but the UCLA team is the first to document it, said Dr. Neil Wenger, professor of medicine in the division of general internal medicine and health services research at the David Geffen School of Medicine at UCLA and the paper's lead author.

"The amazing thing is that this is an easily solvable problem because the state has a database that can identify most of the patients who die, but current law prevents them from giving it to health care institutions; only financial institutions," Wenger said. "Perhaps highlighting this problem will raise awareness and help to fix this issue."

The researchers tracked 11,698 seriously ill patients aged 18 years and older across 41 UCLA Health clinics over two years or until November 2022, and compared those who were noted as being alive in the electronic health record against data in the California Department of Public Health Public Use Death File, a portion of which were then reviewed by hand. This file contains information such as name, sex and birthdate, but not social security number, which is available only for fraud prevention.

Patient encounters included letters, notes, orders, portal messages, telephone outreach, appointments and refills that occurred after death until Dec. 19, 2022.

Of the patients tracked, 2,920 were correctly noted as deceased in their health records but another 676 who were believed to be alive based on their records were in fact deceased according to the California data.

Of those found to be deceased 541 had an encounter or appointment still pending. In addition:

- 221 received 920 letters about preventative care such as flu shots or cancer screenings
- 166 received 226 mailed correspondence
- 158 had 184 orders placed for vaccines and other care
- 88 medications were authorized
- 310 appointments were still active for 145 deceased [patients](#)

Follow up extended for an average of 19 months.

"Not knowing who is dead hinders efficient health management, billing, advanced illness interventions and measurement," they write. "It impedes the [health](#) system's ability to learn from adverse outcomes, to implement quality improvement and to provide support for families."

The findings may not be applicable to other [health systems](#) or states, the researchers note.

Co-authors are Fernando Javier Sanz Vidorreta, Michael Dudley, and Dr. Anne Walling of UCLA, and Dr. Michael Hogarth of UC San Diego.

More information: Consequences of a Health System Not Knowing Which Patients Are Deceased, *JAMA Internal Medicine* (2023).

Provided by University of California, Los Angeles

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