

The Upshot
PUBLIC HEALTH

Release Your Medical Records? First, You Must Collect Them

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One of [Donald J. Trump's](#) recent attack lines against [Hillary Clinton](#) focuses on her health: If she has nothing to hide, he asks in a tweet, why doesn't she release her medical records to the public?

For the moment, put aside Mr. Trump's own revelations about his medical history, which consist of a hyperbolic, undated letter with little detail from his gastroenterologist. And put aside Mrs. Clinton's own recent disclosures, which include a somewhat more detailed accounting of her health and medication history from the internist who has overseen her care in recent years. Put aside, finally, the question of whether complete medical records would allay the conspiracy theories of some of Mrs. Clinton's critics, who say a recent cough is a sign of disqualifying illness or believe she experienced a seizure during a recent news conference.

Instead, assume that Mrs. Clinton wished to take Mr. Trump's request seriously, and release full and detailed medical records. It would not be easy, even for a V.I.P. with an army of staffers. Mrs. Clinton is 68 years old, has lived in multiple states and been treated by many doctors and hospitals over the years. The notion of a single file, containing "medical records," is a fiction. Her medical records are in bits and pieces, in doctors' filing cabinets, hospital records departments, and in hard-to-access computers. Just like yours, probably.

The federal government has invested billions in helping to digitize medical records, but the process is still in its infancy, with data that is often nonstandard and hard to transfer between systems. And even as a growing number of medical professionals have made the transition to digital records, most of our medical histories exist only in the old world of paper, assuming they still exist at all. (Mrs. Clinton's pediatrician is unlikely to still be alive, and records of Mrs. Clinton's possible polio vaccination or childhood ear infections may be lost to history.)

"Getting someone's records is a nightmare, because they are in paper, and they're scattered everywhere," said Dr. William Tierney, the department chairman of population health at the Dell Medical School at the University of Texas, who has studied and worked on electronic health records systems, and used them as a physician.

Obtaining a complete set of Mrs. Clinton's health records would require a perfect accounting of every doctor's office she has visited in her life, and then requests for copies of the records that still exist. Collecting records can be challenging for patients: Doctors and hospitals, fearful of inadvertently violating federal medical privacy laws or simply reluctant to put in the legwork, often refuse to email or even mail records to patients. And even when medical providers comply with requests, the results can be confusing and inconvenient — requiring fax machines, CD-ROM discs with unfamiliar file formats, or photocopies of pages in a physician's scrawl.

"Average people encounter a huge amount of difficulty," said David Blumenthal, a former national coordinator for health information technology for the Obama administration, now president of the Commonwealth Fund. He said he had heard countless stories of patients sent to the basement and asked to pay by the page for printouts of digital records.

Good luck reading those records when you get them: pages of lab readings, check-box answers, billing codes and illegible handwriting. Few patients can understand the records, and neither can many physicians. That's why, even in the most wired of medical offices, receptionists still hand you a clipboard and ask you to write your medical history before the doctor will see you.

“It’s the last bastion of paper,” said Casey Quinlan, a Virginia-based writer who became a patient advocate after the frustrations of managing care for her parents and then herself, when she was treated for breast cancer. “The fax machine is still strong in this one.”

Ms. Quinlan, who travels to health and technology conferences arguing for a better system, has had a large QR code — a type of bar code to store and track data — tattooed on her sternum. Medical providers are invited to scan the image, which she linked to a password-protected site with key medical information.

In 1999 and again in 2008, Senator John McCain released more than a thousand pages of his medical records to reporters. But his was the exception that proved the rule. A Navy veteran and a former prisoner of war, Mr. McCain was part of a long-term study in the military health system, so many of the relevant records really were all in one place. But in later years, he was treated at the Mayo Clinic, and the campaign said it had been forced to postpone the records release because of difficulties with wrangling different doctors within that one system.

By historical standards, neither candidate in this election has been particularly forthcoming about matters of health, despite being older than typical for the job they seek. While candidates in the past may not have published comprehensive reams of documents, most did provide more than a short doctor’s note. Given the complexity of collecting and interpreting medical records, something in between might help the public better assess the health of the candidates hoping to lead the country. (Dan Diamond at Politico recently wrote about one intriguing idea: a panel of independent physicians who would evaluate every candidate on the public’s behalf.)

But if the standard is detailed medical records, Mr. Trump might also struggle with the same challenges of technology, logistics and clarity that afflict college freshmen trying to confirm their vaccination records; or weekend warriors wishing to bring an M.R.I. to a sports medicine doctor; or cancer patients seeking a second opinion. Or anyone with a chronic illness who has ever moved. (Even someone with “astonishingly excellent” test results has probably seen a few medical providers in 70 years.)

Dr. Tierney worked for years in Indiana to help the state develop a cutting-edge health information exchange, a place where most of the state's hospitals shared patients' medical data. After 44 years in the state, he queried the exchange for his records before leaving. He paid \$100 for an inch-and-a-half-thick stack of papers.

"I went to my new doctor," he said. "I put it on the table. And she said, fill out the form."

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Casey Quinlan is a patient advocate who has a tattoo of a QR code — a type of bar code to store and track data — for her medical records. Chet Strange for The New York Times