



INTEROPERABILITY AND CANCER CARE: A Primer for Patient Advocates

What is interoperability? Why does it matter?

Interoperability is the ability of different computerized health data systems to easily share and make sense of medical information. As medical records become increasingly digitized, and as the volume of clinical research grows, the speed and ease with which health care providers can access and apply health information can determine the quality of care that patients receive.

Interoperability is a critical but underappreciated component of modern health care. When physicians and patients can securely and easily share data, it can lead to better coordinated and more efficient care. It also can help a patient and his or her physician make better informed treatment decisions by providing faster access to the latest information, alerting physicians to key changes in a patient's medical history, and making it easier for different members of a patient's medical team to work together.

How does a lack of interoperability harm cancer patients?

Unfortunately, we are still far from achieving interoperability. And without interoperability, patients and patient care suffer because physicians may not have access to the latest and most accurate information on the patient. This can lead to:

- Redundant or unsuitable patient care, such as specialists not being given or having access to a patient's full medical record
- Added and unnecessary costs for care and treatments
- Needless travel and additional expenses for patients who have to physically carry health records between providers
- Long wait times at the doctor's office while the practice waits to receive information from another provider or specialist
- Missed opportunities to apply treatment insights that would have been helpful if they had been accessible

In a recent poll of cancer patient advocates conducted by ASCO, 80% said they would describe the experience of sharing health data between providers as "difficult" or "very difficult."¹

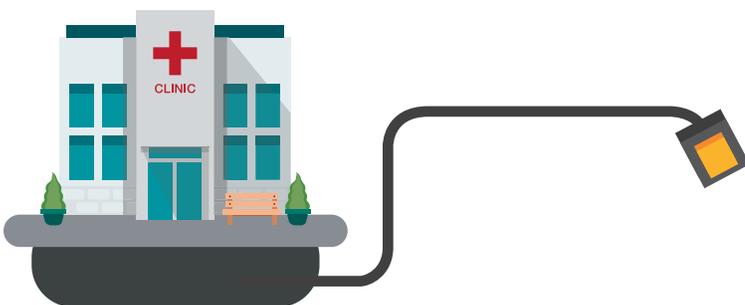
These advocates cited many examples of how a lack of interoperability affected their care or the care of people they know.

- For instance, one advocate described the care he receives in a single health care system that uses multiple EHR systems. The oncology department could not see his scheduled appointment or lab information that had been entered by the radiation department of the same health care system, and a simple request for pain medication on a Friday afternoon was unnecessarily difficult to fulfill.
- Another described the experience of an 80-year-old woman who had to travel to her local hospital to retrieve medical records to send to another provider. She then had to buy a fax machine and get it set up so that she could fax her information to her care providers.

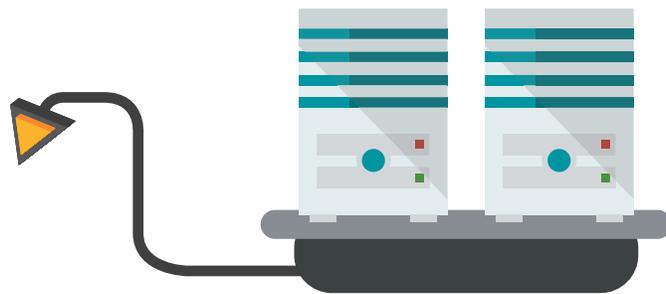
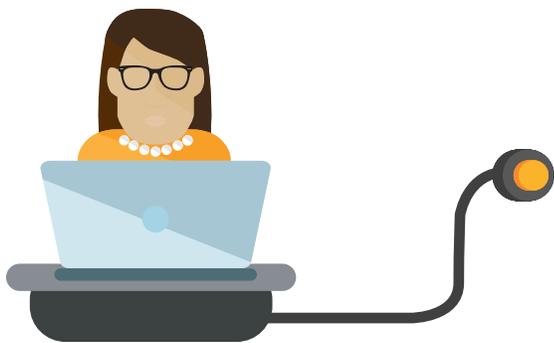
In the age of smartphones and big data, patients should not have to experience these kinds of difficulties.

"[The] transfer of records is complicated, mysterious, and fraught with hazards."

– Patient advocate, ASCO survey



American Society of Clinical Oncology



How does a lack of interoperability imperil patients and progress against cancer?

The inability to share and exchange information also can undermine national efforts underway to improve the overall quality and value of patient care. The promise of precision medicine hinges on vastly improved, secure sharing of genomic data, clinical data and other information.

Most recently, Vice President Joe Biden, as part of his “moonshot” to cure cancer, singled out data sharing as a key strategy to advance progress in cancer care. He called on public and private partners to work together to break down data silos where they exist and to expand the shared pool of knowledge to improve how we treat cancer.

There are several such data initiatives in development, including ASCO’s CancerLinQ™, that aim to connect and analyze real-world cancer care data so that doctors can draw new insights and provide better care for patients. The success of initiatives like this depends on the ability to securely share patient health information.

Where do we stand on interoperability today?

The federal government and health care providers have invested billions of dollars to implement electronic health record systems and achieve interoperability. Unfortunately, these efforts have come up far short of where we need to be. Physicians and hospitals report:

- When treating patients, only 41% of hospitals have routine access to patient data outside their own networks.²
- Less than half of hospitals say they integrate data they receive into individual patient records.²
- EHR implementation and data sharing was the #1 concern among oncologists surveyed by ASCO in 2015, when asked to describe the top pressures that affect their practices.³

There are a number of factors that contribute to the lack of interoperability. These include the obvious technical challenge of connecting numerous systems, the lack of commercial de facto and government standards, but also the difficulty of transforming the basic way in which we receive, access, and share patient information in an increasingly complex and fragmented health care system.

“[Interoperability] could be a life or death situation...”

– Patient advocate, ASCO survey

How can advocates help advance interoperability?

Advocates play a critical role in bringing attention to this issue by educating patients and making sure it stays at the forefront of stakeholders’ and policymakers’ minds. You know firsthand the difficulties patients face when receiving care. Increased awareness and action are needed so that we can achieve the collective goal of full data integration.²

Today, the Department of Health and Human Services’ (HHS) Office of the National Coordinator for Health Information Technology (ONC) is charged with advancing health IT adoption and has outlined a roadmap for achieving interoperability by 2024, available [here](#). ASCO and many other organizations also work on achieving interoperability, for example through ASCO’s CancerLinQ big data initiative.

But we need your help. Please talk to your fellow advocates about the issue. Share this backgrounder and connect with others in your community to identify ways you can help advance this issue.

Some crucial actions include:

- Demanding more legislative action from Congress to encourage data sharing and prevent the unnecessary blocking of patient data
- Making your concerns known to providers, EHR companies, and others charged with ensuring that EHR information can be safely and securely shared to improve patient care and advance progress against cancer

1. American Society of Clinical Oncology (2016). *Survey on Interoperability of Patient Records in Cancer Care* [data file].

2. The Office of the National Coordinator for Health Information Technology. *Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap*. Final version 1.0, 2015. <http://www.healthit.gov>

3. American Society of Clinical Oncology. *The State of Cancer Care in America, 2016: A Report by the American Society of Clinical Oncology* [published online ahead of print March 15, 2016]. *J Oncol Pract*. doi:10.1200/JOP.2015.010462.



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