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The Honorable Diana DeGette
United States House of Representatives
2111 Rayburn House Office Building
Washington, DC 20515

The Honorable Fred Upton
United States House of Representatives
2183 Rayburn House Office Building
Washington, DC 20515

Dear Representatives DeGette and Upton,

Thank you for your leadership in introducing the bipartisan Cures 2.0 legislation, which provides an opportunity to transform innovation in health care. The Pew Charitable Trusts is a non-profit research and policy organization with several initiatives focused on improving the quality and safety of patient care. Pew's health information technology initiative focuses on advancing the interoperable exchange of health data and improving the safe use of electronic health records (EHRs). We greatly appreciate the opportunity to share relevant research and findings impacting key concepts outlined throughout the legislation—principally those affecting health IT and public health infrastructure.

For the past year and a half, the nation has undergone one of the worst public health disasters in our history. While there are many lessons to take away from the COVID-19 pandemic, a core message is that health IT and public health infrastructure are the foundations of pandemic monitoring and response efforts and must be prioritized going forward. While many of the policy changes in Cures 2.0 address these important principles, key gaps remain—particularly in patient matching, health IT infrastructure, and data exchange with public health agencies.

For example, state and local health departments rely on the daily intake of data from hospitals, doctors' offices, laboratories, and other health care facilities to inform a range of public health initiatives—including those that could help respond to larger crises or require immediate action by health officials, like COVID-19. These data help authorities follow up with individuals directly to conduct case investigations, identify outbreaks within communities, evaluate disease control programs, set critical policy to protect the most vulnerable, and connect people to other health services or treatments. Additionally, other key data sources, such as lab results and vaccination records, are necessary for effectively re-opening the country—and ensuring it is safe to keep open. Unfortunately, significant gaps in the data available to public health authorities have hindered the exact actions that could help the country emerge from the COVID-19 pandemic, save lives, and restart the economy.

Additionally, many of the plans to continue reopening the country rely on effective contact tracing and the continued deployment of vaccines. However, flaws in the identification and matching of patient records inhibit both these factors. For contact tracing, public health agencies rely on having correct demographic data—such as names and phone numbers—to identify individuals that test positive and contact them to determine whether anyone else may need to

self-isolate. Yet, public health authorities will often receive incomplete data, and spend days looking for phone numbers or other contact information to locate an individual and begin contact tracing—all while the virus spreads unimpeded. Similarly, vaccine registries play an important role in giving clinicians accurate and up-to-date information on a patient’s vaccination status. The inability to find the right record can result in patients getting the wrong number of doses, or a second dose of a different vaccine.

As the country continues to take steps to emerge from the pandemic—and better prepare for future crises—several steps can be taken to help ensure a data-informed response.

Patient Matching

Patient matching, or the ability to accurately link each individual’s records from multiple doctors’ offices or hospitals, remains a perennial problem in health care. As the pandemic demonstrated, accurate patient matching is crucial not just for direct patient care, but also for public health outreach. COVID response efforts, and any future pandemic response, hinge on public health authorities having complete data for accurate patient identification and matching. However, research shows that this is often not the case. For example, laboratories often do not send phone numbers to public health authorities with test results, and when they are included, the numbers often refer to an ordering physician and not a patient.¹ This not only complicates reaching the patient and conducting contact tracing, but it also makes matching across lab information systems and other systems—like EHRs and public health registries—challenging. Similarly, patients’ addresses remain an unrequired data element in lab orders and messages, leaving minimal data to use for patient matching.

Even when systems share the same data, certain elements—such as addresses and phone numbers—may not be standardized to the same format, inhibiting successful matching. Research has shown that standardizing specific data elements can improve match rates. Use of the U.S. Postal Service (USPS) format for address (which indicates appropriate street suffixes, among other things) can improve the accuracy of matching records by approximately 3%, which could result in tens of thousands of additional correct record linkages per day.² An organization with a match rate of 85%, for example, could see its unlinked records reduced by 20% with standardization of address alone.

In the regulations implementing the initial Cures legislation, the Office of the National Coordinator for Health Information Technology (ONC) did not adopt the USPS standard for address, stating that it allowed for variation, which could result in multiple “valid” addresses. While possible, the use of a standard would still drastically improve match rates overall. Today, the process for entering addresses within health IT systems does not include any steps to check for basic standardization, like making “St” and “Ave” consistent, and formatting the final four-digit zip code. Inconsistent documentation, in addition to data entry mistakes, produces higher variation among addresses than the USPS standard would allow.

Further, ONC stated that the implementation of the available USPS standard would create a burden on provider organizations. However, vendors would be responsible for developing and implementing the standard within health IT systems—not providers. Additionally, USPS

operates a free service to conduct this standardization today that is used widely by the shipping industry. Were this service made available for use in health care, it would significantly reduce implementation burdens.

Many immunization registries (and the information systems they use) have already recognized the value of using the USPS address format for patient matching, and pay to use a shared service to conduct this standardization and validation.³ They experienced improvements in patient matching and de-duplication within their systems, and also gained, on average, a 12% increase in mail deliverability when conducting community outreach.⁴

Despite the availability of the USPS address standardization web tools for free to online retailers and e-commerce, the agency's terms and conditions restrict its use solely for shipping purposes. As a result, health organizations cannot use it for patient safety and pandemic response even though it is already available to those other services. As a benefit to future pandemic response efforts, ONC should require the USPS address standard for all health IT systems, and coordinate with the USPS to make their technology available for free within health care.

Given the critical importance of patients, providers, and public health systems receiving and sharing accurate and complete results and associated demographic information, all health information technology systems should collect and exchange complete demographic information and utilize the USPS address standard to do so.

Electronic reporting of public health data

Gaps in public health data have hindered the exact actions needed to emerge from the COVID-19 pandemic and restart the economy. For example, epidemiologists have indicated that patients' contact information is missing in more than half of COVID-19 lab results, while demographic information, such as race and ethnicity, is absent in 85% of them.⁵ Manual case reporting, or the non-electronic transmission of results through methods such as faxes, also results in widespread under-reporting. The Centers for Disease Control and Prevention estimates that, in some circumstances, as few as 1 in 10 reportable cases are sent to public health agencies after a medical encounter.⁶ Additionally, from early COVID-19 vaccine reporting, data on race and ethnicity was present in only 51.9% of cases.⁷ Without this information, officials cannot adequately track the spread of a public health threat or understand its impact on different communities.

Were the Federal government to require electronic data sharing to public health agencies that meets ONC-determined data standards, public health officials would have the complete, timely and standardized data needed to inform interventions and curb disease spread. This can be accomplished by requiring the Centers for Medicare and Medicaid Services (CMS) to include a reporting mandate for public health data in the Promoting Interoperability payment program. Specifically, for any data collected—including patient-generated data—existing standards such as SNOMED and LOINC should be used to capture this data. If standards would need to be developed for these or other purposes, ONC could work with stakeholders and standards development organizations to do so. Standardized data provides an opportunity to have clinical data, including patient generated data, collected in ways that are consistent and comparable across different systems, health care organizations, and locations.

Vaccine and immunization system support and upgrades

Vaccine data are stored in immunization information systems (IIS), also called immunization or vaccine registries. These systems provide consolidated records of an individual's vaccination history, along with clinical decision support about immunizations that are due. Health professionals and clinicians rely on IISs to assist with assessing and evaluating a patient's current immunization status and determining whether to administer a dose. For example, prior to administering vaccines, clinicians should check the relevant IIS for a patient's record to determine whether vaccines are needed, and, following administration, report immunizations that were given. At the population level, IISs provide aggregate data on vaccinations for use in surveillance and program operations, and in guiding public health action to improve vaccination rates, reduce vaccine-preventable diseases, and address vaccine-preventable disease outbreaks.

Immunization registries have existed for more than 25 years and have been a source of data for immunization records—from varying sources—long before EHRs were widely used. Increasingly, pharmacies, hospitals, doctor offices and other locations can both query information from IISs at the point of care and report data back into them.

There are currently a total of 64 immunization registries across all 50 states, five cities, the District of Columbia, and eight territories. As of 2018, IISs captured 95% of the 0-6-year-old population and 80% of the adolescent population (age 11-17 years), but only 56% of adults over 19 years old.⁸ As a result, major gaps exist in the use of these systems. However, reporting to IISs for all patients is often not a state-level requirement; likewise, there are no federal regulations or incentives for reporting data on all patients to jurisdictional IISs.

Additionally, because bidirectional exchange—the ability to send and receive information between systems—is a component of the optional public health requirements in EHR certification and in the Promoting Interoperability program, some EHRs have the capacity to accept and display data from IISs as well. Such integration reduces the number of systems that users need to use to determine current immunization status. However, not all EHRs have this functionality; those that do may not have it widely implemented in practice. Such optionality creates gaps in data submission to IISs; this functionality should be required by ONC.

The COVID-19 pandemic has also illustrated the vital role IISs play in pandemic response. Real-time, complete data on all patients, regardless of age, is needed to aid the vaccination campaign. However, from early COVID-19 vaccine reporting, data on race and ethnicity is present in only 51.9% of cases. These gaps hamper the ability of public health authorities to identify and address disparities in access or uptake.⁹

In order to maximize use of vaccine registries throughout public health emergencies, and non-emergencies alike, the federal government should incentivize reporting into IISs for all patients, regardless of age, through programs such as Promoting Interoperability or the Quality Payment Program. Additionally, ONC should move to mandate bi-directional integration with IIS systems in all certified technology so that EHRs have the mechanisms to exchange vaccine information. Lastly, both ONC and CMS should require that public health reporting meets data standards to

ensure information is complete and consistent. Requiring connections to IISs, and ensuring adherence to data standards, can help increase incoming data and improve its quality and completeness.

Widespread adoption of application programming interfaces

The creation of an agency to pilot the use of innovative technologies—such as the proposed Advanced Research Projects Agency for Health, or ARPA-H—could act as a testing center for expanding the ways in which data is exchanged, analyzed, and utilized. Application programming interfaces, or APIs, are tools that can help gather and exchange standardized information among different systems. These tools could be piloted and tested in such an agency to leverage timely, electronic reporting to public health agencies, or used for active querying of data rather than using traditional data-sharing methods. Having a center where such new technologies or new applications of existing technology are central to its mission would help increase the adoption and usability of these tools.

Conclusion

The COVID-19 pandemic highlighted gaps in data exchange that limited the effectiveness of public health action and failed to make the most of existing technologies. Research shows that by addressing key challenges in patient matching, health IT infrastructure, and data exchange with public health agencies, the nation will be better prepared for current and future health emergencies. Going forward, the federal government can implement these data-driven solutions to build a stronger foundation of health infrastructure:

- All health information technology systems should collect and exchange complete demographic information, and utilize the USPS address standard to do so;
- CMS should include a reporting mandate for public health data in the Promoting Interoperability payment program;
- ONC should include bi-directional exchange with IIS' as a required component of EHR certification; and,
- All public health reporting requirements should include an adherence to national standards.

Should you have any questions, or if we can be of assistance, please contact Elise Ackley at 202-540-6464 or eackley@pewtrusts.org.



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¹ B. Dixon et al., “Electronic Health Information Quality Challenges and Interventions to Improve Public Health Surveillance Data and Practice,” *Public Health Reports* 128, no. 6 (2013): 546-53, <http://europepmc.org/article/PMC/3804098>.

² S.J. Grannis et al., “Evaluating the Effect of Data Standardization and Validation on Patient Matching Accuracy,” *Journal of the American Medical Informatics Association* 26, no. 5 (2019): 447–56, <https://doi.org/10.1093/jamia/ocy191>.

³ American Immunization Registry Association, “Address Cleansing Service,” accessed April 30, 2020, <https://www.immregistries.org/address-cleansing>.

⁴ American Immunization Registry Association, “Pilot Summary, Address Cleansing & Geocoding Services,” accessed May 11, 2020, March 15, 2017, <https://repository.immregistries.org/resource/pilot-summary-address-cleansing-geocoding-services/>.

⁵ R. Pifer, “Public Health Agencies, Commercial Labs Warn Patchy IT Infrastructure Hobbling COVID-19 Response,” Health Care Dive, <https://www.healthcaredive.com/news/public-health-commercial-labs-CDC-health-it-coronavirus-covid19-test/576189/>.

⁶ L.A. Conn et al., “eCR Now: A Webinar Describing Efforts to Scale Ecase Reporting Nationwide” (presentation, AMIA 2020 COVID-19 Webinar Series, April 28, 2020), <https://www.amia.org/education/live-webinars/ecr-now-webinar-describing-efforts-scale-ecase-reporting-nationwide>.

⁷ E.M. Painter et al., “Demographic Characteristics of Persons Vaccinated During the First Month of the COVID-19 Vaccination Program,” *Morbidity and Mortality Weekly Report* 70, no. 5 (February 5, 2021): 174-77, <https://www.cdc.gov/mmwr/volumes/70/wr/pdfs/mm7005e1-H.pdf>.

⁸ Centers for Disease Control and Prevention, “2018 IISAR Data Participation Rates,” last modified December 12, 2018, <https://www.cdc.gov/vaccines/programs/iis/annual-report-iisar/2018-data.html>.

⁹ Painter et al., “Demographic Characteristics of Persons Vaccinated During the First Month of the COVID-19 Vaccination Program.”