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Data in Crisis — Rethinking Disaster Preparedness in the United States

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In 2017, Hurricane Maria's devastating impact in Puerto Rico exposed significant flaws in the United States' medical and public health response to natural disasters. The majority of the nearly 3000 excess deaths caused by the hurricane were attributable not to its immediate, direct impact, but to the persistent, indirect effects of delayed medical care and disrupted access.[1,2] Studies have consistently shown that indirect effects from natural disasters like Hurricane Maria disproportionately affect poor, elderly, and structurally disadvantaged populations.[1–3]

When medical centers and transportation infrastructure are damaged, patients who need chronic care such as dialysis, wound care, or chemotherapy seek to resume care at alternative sites, or else risk substantial harm or even death. Power outages, such as those that affected more than 4 million households in Texas during winter storms in February 2021, also place Americans at risk in their own homes; people who rely on electric medical equipment such as nebulizers, continuous positive airway pressure (CPAP) machines, or infusion pumps are particularly vulnerable.[4] Evacuation, a common response to natural disasters such as the wildfires in California or hurricanes in the Gulf of Mexico, similarly endangers the health of people dependent on medical and social services such as visiting nurses, meals-on-wheels, or home health aides, as elderly and vulnerable people struggle to reestablish care in a new health system and jurisdiction.

Despite the need to address these long-lasting indirect effects of disasters, hospitals, health care coalitions, and response agencies are mainly focused on preparing for mass-casualty incidents and large influxes of patients, or on evacuations and safe transfers

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after a facility has been damaged.[5,6] Disaster-preparedness simulations are designed to test facility-based preparedness; they seldom test for community-based preparedness. Federal agencies including the Center for Disease Control and Prevention (CDC) and the Office of the Assistant Secretary for Preparedness and Response (ASPR) have developed tools like *MedCon: Pre-Event* or *emPOWER* that help establish baseline medical needs in displaced communities, but few health departments have the know-how or resources to use them.[7] Despite the fact that natural disasters are expected to increase in frequency and severity in the coming years, our public health preparedness and response — as our national experiences from natural disasters and pandemics have shown — is often woefully inadequate.[8,9]

In recent years, large-scale streams of digital data on medical needs, population vulnerabilities, physical and medical infrastructure, human mobility, and environmental conditions have become available in near-real time.[10,11] Sophisticated analytic methods for combining them meaningfully are being developed and rapidly evolving.[12–14] However, the translation of these data and methods into improved disaster response faces substantial challenges. The data exist but are not readily accessible to hospitals and response agencies. The analytic pipelines to rapidly translate them into policy-relevant insights are lacking, and there is no clear designation of responsibility or mandate to integrate them into disaster-mitigation or -response strategies. Building these integrated translational pipelines that use data rapidly and effectively to address the health effects of natural disasters will require substantial investments, which will, in turn, rely on clear evidence of which approaches actually improve outcomes. Public health institutions face some ongoing barriers to achieving this goal, but promising solutions are available.

Mapping Baseline Vulnerabilities

Local response agencies require access to baseline maps that identify both populations' medical vulnerabilities (e.g., age, coexisting conditions, use of electricity-dependent durable medical equipment) and structural vulnerabilities (e.g., housing status, transport options, food insecurity). Accurate baseline vulnerability data are critical to understanding and responding to the uneven patterns of morbidity and mortality that already exist among communities and that are exacerbated during disasters. Remarkably, although comprehensive patient profiles are routinely constructed from electronic medical records, pharmacy data, and claims data — to be traded and sold commercially — they are not readily available to patients, hospitals, or response planners.[15] Similarly, although technology companies have extensive data on user habits, location, and mobility patterns, relevant aggregated data sets or analyses are seldom shared with public health response agencies.[16]

Over the past decade, health information exchanges have been developed to create comprehensive patient profiles, but participation options vary widely from state to state, resulting in incomplete data.[17] In 2015, the ASPR partnered with the Centers for Medicaid and Medicare Services (CMS) to develop emPOWER, a publicly available database including information on 4.2 million Medicare beneficiaries who are dependent on durable medical equipment.[18] During public health emergencies, local officials can request disaggregated emPOWER data to target their response.

Though these data include the majority of patients requiring durable medical equipment, they do not include the 85% of Americans who are not enrolled in Medicare (Medicaid patients are expected to be included in the future). Response agencies are not universally trained in the use of these data, so health departments often have to invest substantial resources to act on them — for example, by paying third-party providers to procure the phone numbers of patients included in the identifiable data set. Furthermore, to date there is little publicly available information on the use of emPOWER data and their impact, so their value remains unclear. Efforts to map structural vulnerabilities in medically relevant ways are also currently disjointed, originating in academia, at the state level, or through federal-level efforts.[19–21] During the pandemic, private corporations, contractors, and federal agencies including the CDC, HHS, and the Department of Defense began integrating vulnerability mapping into their Covid-19 response strategies and vaccine distribution.[22,23] Few of these data sets are updated on a regular basis, however, or reside in publicly available, standardized databases to facilitate access and analysis.

Rapid Analysis of Unconventional Data Streams

Anticipating the dynamics of post-disaster medical needs also remains mostly guesswork. The changing conditions caused by a natural disaster must be integrated into response plans, requiring up-to-date information on weather, infrastructure damage, and evacuation, which will determine the nature, scope, and location of health needs. Both retrospective analyses of characteristic patterns of medical needs after various kinds of natural disasters and the development of pipelines to integrate near-real-time data in order to anticipate and respond to crises will be critical. Real-time access to unconventional data sources is now possible, with advances in remote sensing of smoke plumes, floods, and infrastructure damage from satellite images[24]; real-time, public access to standardized air-quality data from distributed sensors[25]; and increasingly available aggregated human-mobility data from mobile phones.[26] Creating appropriate analytic tools and pipelines to support rapid integration of these data into outputs relevant for decision making, in near-real time, is a crucial next step.

After Hurricane Maria, we conducted a retrospective analysis using data from mobile phones, social media, and air travel, to show that rapid migration from rural to urban centers, as well as from Puerto Rico to the mainland United States, occurred after the hurricane.[27] Such mobility patterns would have had important implications not only for the allocation of aid and the anticipation of patient needs at medical facilities after evacuations, but also for estimation of basic epidemiologic parameters such as mortality rates or incidence of disease. At that time, however, the translational pipeline for integrating analysis from mobility data into public health policymaking was slow and lacked a clear reporting structure, so the study could not be more than a proof of concept.

Similarly, in anticipation of Cyclone Kenneth in Mozambique in 2019, we developed a risk model to support the allocation of cholera vaccines, in order to prevent cholera outbreaks from occurring in its wake.[28] Using vulnerability metrics based on previous cholera risk and a mobility model, as well as projected flooding and climate data on sensitivity to El Niño, we accurately predicted the highest-risk regions, but the lack of transparency about how analytic outputs were used in decision making made it difficult to assess the operational utility of these predictions.

The Covid-19 pandemic, however, has improved not only access to these data sets but also policymakers' interest in using them. In 2020, scientists from the Covid-19 Mobility Data Network — to which we belonged — used aggregated mobility data from social media companies to predict population movement after Hurricane Laura and then worked with officials to place emergency-response teams and shelters to accommodate displaced communities.[29]

New data streams that help track environmental conditions, infrastructure, and population mobility are not traditionally considered to be medical or population health data, and yet they have been repeatedly shown to provide critical epidemiologic insights.[30] Targeted research funding is needed to advance and to validate the utility of applying these data streams in disaster planning. For data from private corporations, such as those from mobile phone or social media companies, regulatory and scientific consensus is needed to develop standardized approaches to protecting individual privacy by means of aggregation and anonymization.[31,32] Nevertheless, with appropriate baseline vulnerabilities mapped, these dynamic data streams can strengthen disaster simulation and response. Just as routine forecasting for epidemics is an important goal for pandemic preparedness, anticipating both the immediate surge in patients and the longer-term dynamics of the medical needs of communities displaced in the wake of natural disasters should become the norm.

Mandate

Substantial regulatory changes and financial incentives are required if these data pipelines are to be sustained and integrated into routine disaster response. The technology exits to allow local data to flow upstream to state or federal response agencies, in real time. The mandate does not. Although CMS has sought to stimulate improvements in facility-based emergency preparedness, there is generally no obligation on either health systems or departments of health to ensure continuity of chronic care.[33] In fact, it is hard to ascribe such responsibility to any single hospital, since patients may seek care from multiple institutions. People of color, people experiencing homelessness, people with disabilities, and people without insurance often do not seek routine primary care and are least likely to be accounted for.

The Covid-19 pandemic has generated renewed interest in data sharing and integration across the health system. It will be important to sustain and consolidate this progress. The CDC expanded its online disease-surveillance tracker, COVIDView to include weekly information on Covid-19–related emergency visits, hospitalizations, deaths, laboratory data, vaccination and even racial/ethnic disparities. Health care coalitions around the country cooperated to routinely share bed-occupancy information and aggregated clinical data, but in the absence of preexisting automated data pipelines, the reporting entailed manual collation and exchange of spreadsheets and faxes and was needlessly onerous. Health care coalitions are under-resourced, however, and should be funded to maintain such databases and to develop local or regional capacity for analyzing the data. It would be unreasonable to expect every small health care facility (such as a federally qualified health center, for example) to bear associated operational and analytic costs.

CMS can consider expanding the scope of its Emergency Preparedness rule (2016 and 2019) — which mandates facility-based preparedness requirements for natural and human-made disasters, as well as interagency coordination — to require hospitals to contribute these data to health care coalitions during emergencies. CMS could also consider doing so under its Promoting Interoperability Programs.[34] Under the Health Information Technology for Economic and Clinical Health (HITECH) Act, the executive branch could also mandate sharing of data relevant to public health emergency planning.[35] As of April 5, 2021, the information blocking (prevention) provision of the 21st Century Cures Act went into effect, finally mandating portability of health information and instituting hefty fines for noncompliance.

Leveraging the progress made in 2020, Congress should make the availability of reliable vulnerability maps and human-mobility data part of our national response data infrastructure. New and existing application program interfaces (APIs) can facilitate timely, automated exchange. Data management, processing, analytic and local translational capability need an overhaul. Much work is needed to identify the types of data and the terms under which they can be exchanged easily during emergencies, as well as the types of personnel and agencies that may access such data, and to balance the risks posed by automation against potential benefit to individuals and groups.

To protect our most vulnerable communities from increasingly frequent climate-related extreme weather events, public health agencies and hospitals need to know — before, during, and after a disaster — who and where these vulnerable people are, their hazard-specific risks, and whether they have been displaced from their networks of care. We have all the necessary building blocks in place to ensure that this information gets where it needs to go, but sustained commitment and investment in the necessary data systems, methodologic tools, and translational pipelines will be required to prepare for the natural disasters facing us.

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