Call for Position Statements on Responsible Uses of Technology and Health Data During Times of Crisis 9/21/2020

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An international pandemic with tremendous health outcome disparities across race and ethnicity, coupled with long overdue social unrest demanding racial justice, has laid bare our insufficient data infrastructure to improve social outcomes. The effectiveness of local, state, and federal response to COVID-19 is dependent upon data-informed decision-making. However, these decisions frequently rely on problematic data that are plagued by insufficient data flow, data quality issues, and data granularity that are often insufficient to support a clear path of action. These data are largely held by public institutions that are often mistrusted by the public they serve, compounding the challenge of effectively using data to drive policy decisions.

Yet, there are bright spots. Jurisdictions across the US, with established integrated data capacity and strong vertical and horizontal communication pathways, have been nimble and responsive to the needs presented by the pandemic. This capacity does not rely upon sophisticated technical approaches; rather, it is enabled through strategic partnerships across agencies, collaboratively created processes to securely share individual-level data, and privacy protections that make these data actionable.

For example, New York City's <u>Center for Innovation through Data Intelligence (CIDI)</u> leveraged their existing vulnerability mapping tools to help other City agencies and community organizations provide emergency assistance in response to the COVID-19 pandemic. The <u>Identification and Mapping System</u> <u>for Vulnerable Populations</u> was developed by integrating data from NYC's Health and Human Services agencies in order to define, identify, and map high concentrations of vulnerable populations. The system <u>showcases geographical clusters</u> of vulnerable people throughout NYC as well as each neighborhood's concentration of shelter sites, housing authority buildings, and retirement communities. CIDI quickly repurposed their existing vulnerability mapping capacity to address emerging priorities in a timely manner to aid deployment of emergency response teams.

In Los Angeles County, California, researchers are working with the Enterprise Linkages Project (ELP)—an integrated data system hosted by LA Chief Information Office—to assess the impacts of the pandemic

on the unhoused population and target response accordingly. By linking information from health care and homeless management information systems (HMIS), researchers were able to assess discreet levels of vulnerability among the elderly homeless population (65+), propose housing and service models that matched those levels of vulnerability, and estimate potential cost offsets to Medicaid and the County that would help recapture funds needed to help stabilize people in housing, including move-in costs, varying subsidy approaches, and case management services.

The California Policy Lab (CPL) is also using ELP data to predict risk of homelessness among single adults and families with LA County service histories. CPL published a report on its prediction models in 2019 and is now partnering with LA County to develop pilot prevention programs targeted with the risk models. LA County has a data sharing agreement with CPL permitting them to undertake approved studies on homelessness and high cost utilization of LA County services. The partnerships between university-based researchers, ELP, and CPL demonstrates how existing data capacity can complement projects across institutions and disciplines when guided by a shared mission and sufficient protections and processes in place.

Both LA County and NYC relied upon existing relationships, experience gleaned from similar projects, proximity to the Mayoral office and other data holding agencies, and a long-established sense of trust between parties to leverage existing data sharing pathways to better understand how COVID-19 affects both immediate need and long-lasting impacts in their jurisdictions. Prior work operationalizing concepts of race, ethnicity, and vulnerability meant that these essential concepts were already a part of their analytic lens.

Similarly, at the state level, the <u>California Health and Human Services Agency (CHHS)</u> and <u>USC Children's</u> <u>Data Network</u> were able to leverage existing capacity to build an <u>online tool to connect essential</u> <u>workers to child care providers with open slots</u> after the temporary closure of most daycare centers in the state. In collaboration with the Governor's Office, departments of social services and of education, local resource and referral agencies, Open Lattice, and over 46,000 childcare providers across the state, CDN and CHHS helped build the searchable, web-based interface in 10 days. Not only was <u>mychildcare</u> successful in visualizing, for the first time, the availability of child care slots statewide, it also served as a validation of the <u>Research Data Hub</u>, a secure, cloud-based research enclave for hosting linked research data sets, which was still under development when the pandemic began. Mychildcare data, now hosted within the Research Data Hub, are also being used to answer requests for data from federal and state partners to better capture impact and to facilitate mid- and long-term planning (e.g., the number of facilities open now that weren't open in the prior month, the number of child care slots being requested).

CIDI, ELP, CHHS and CDN, all <u>AISP Network Sites</u>, have established shared data infrastructure that is sufficiently resourced, with clear policies and procedures for data access and use that prioritizes actionable insights without compromising privacy and security. With established governance and legal agreements, these sites are able to use de-identified information quickly and effectively, and in some cases, a governance structure allows for operational use of data when allowable. These cross-sector relationships were developed, cultivated, and maintained prior to the pandemic's onset, and exist outside of crisis response.

These examples support a call to action for government agencies to develop integrated data systems that aid government response in times of crisis, particularly for targeted interventions for those communities most at-risk of disparate impact. Regardless of the crisis—COVID-19, fires, floods, hurricanes, or some other unforeseen challenge—timely and targeted government response is essential. And effective response is dependent upon quality data and clear pathways for cross-agency collaboration to make these data actionable.