League of United Latin American Citizens

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Lead, Information Collection Review Office
Office of Public Health Ethics and Regulations, Office of Science
Centers for Disease Control and Prevention (CDC)
1600 Clifton Road NE, MS-D74
Atlanta, Georgia 30329

RE: LULAC Comment on Extension of Generic Clearance for Emergency Epidemic Investigations (EEIs), OMB Control No. 0920-1011

Dear Dr. Zirgler:

The League of United Latin American Citizens (LULAC), the nation's oldest Latino civil rights organization, submits this comment regarding the Centers for Disease Control and Prevention's (CDC) request for a three-year extension of the Generic Clearance for Emergency Epidemic Investigations (EEIs) under OMB Control No. 0920-1011, scheduled to expire on December 31, 2025.

CDC states that this extension is essential for rapid data collection during unexpected outbreaks—whether biological, chemical, radiological, or of unknown origin. The agency explains that immediate action is necessary to identify causes, prevent public harm, and implement control measures. CDC also notes that participation in these investigations is voluntary, that respondents may include members of the general public, and that data collected may include interviews, surveys, medical record abstraction, laboratory samples, and environmental assessments.

LULAC understands the urgency. When an unknown threat moves through a community, hesitation can cost lives. Public health depends on the ability to act quickly and adapt to evolving conditions. Yet, for the Latino and immigrant families we represent, speed without clearly articulated protections does not feel like safety—it feels like exposure. It is not the pace of the response that raises concern, but the absence of boundaries around how data collected during that urgency may be used.

According to the Urban Institute, one in six adults in immigrant families avoids interacting with public systems because they fear their personal information could be used for immigration enforcement.[1] According to reporting in *Wired Magazine*, Immigration and Customs Enforcement has recently gained unprecedented access to Medicaid beneficiary data affecting tens of millions of individuals.[2] When government institutions collect sensitive data—even for legitimate purposes—the possibility of data migrating into enforcement systems is enough to deter participation. Academic researchers confirm the same: according to McLaughlin and Alfaro-Velcamp, immigrants frequently decline participation in research because disclosing information exposes legal vulnerability.[3] The CDC may call participation voluntary; for many Latino families, saying no is not optional—it is protective..

Language access also determines whether participation is meaningful. Research shows that when clinical trials fail to fully translate consent forms and study materials, Latino participation drops. According to Neuman, Vallejo, Matsuo, and Roman, the absence of translated consent forms directly reduces enrollment in cancer clinical trials.[4] Translation is not a courtesy; it is a prerequisite for informed consent. Likewise, public health often misinterprets immigrant health outcomes by focusing on cultural differences instead of structural barriers. According to Hamilton, immigrant health research is frequently distorted by comparisons that fail to account for context.[5] According to Young and Madrigal, even the documentation of immigration status in research has historically been handled in ways that increase stigma rather than build trust.[6]

These realities require EEIs to do more than move quickly—they must move ethically. CDC can achieve both by adopting safeguards that ensure confidentiality, provide translation and interpretation services, and prevent EEI data from being shared with law enforcement or immigration enforcement. Families will not open their doors if the information they share could be used to harm them. Clear limits on data-sharing—communicated in plain language at the moment of contact—are essential. Transparency in how long data will be retained, how it will be stored, and when it will be destroyed must be part of the EEI process.

LULAC also urges CDC to integrate community health workers—*promotores de salud*—into EEI field teams. These individuals hold trust that government agencies cannot manufacture. According to a national survey published in *Preventing Chronic Disease*, public engagement and participation increase by 26 percent when community health workers are involved.[7] They are the translators of more than language—they are translators of trust.

The CDC emphasizes flexibility. LULAC asks for safeguards. The CDC emphasizes speed. LULAC asks for consent. The CDC emphasizes necessity. LULAC asks for dignity.

For over 96 years, LULAC has defended the rights of Latino and immigrant communities against discrimination, governmental overreach, and the misuse of personal information. The organization was founded during a period when government systems were used to track, target, and intimidate Mexican Americans and migrant families. Across generations, we have learned that civil rights protections are not obstacles to public health—they are the foundation of cooperation. When institutions respect dignity, communities respond with trust. When they do not, communities retreat into silence.

In that history, LULAC has only ever asked one thing of government: Do not ask our people for trust if you are unwilling to guarantee their protection.

CDC's mission and our mission are not at odds. We both seek to protect lives. The EEI clearance should reflect that shared purpose by ensuring that urgency never eclipses civil rights. We stand ready to work with CDC to identify solutions that protect public health without compromising the privacy, dignity, or civil rights of the communities we serve. Should you have any further questions, please contact our National Director of Research and Policy, Dr. Ray Serrano, at rserrano@lulac.org.

Respectfully submitted,

Roman Palomares
LULAC National President and Board Chairman

Works Cited

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