

## Essay

# Casualties of a Pandemic: Truth, Trust and Transparency

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*MICHELLE MARTIN: How important is accurate public information even though it might be frightening?*

*STANLEY MCCHRYSTAL: I think it's critical because if you think about it, what we don't know leaves a vacuum in our mind, and we fill it with the most terrifying ideas. And so I think it's much better for us to get the best information we can, give transparency as best we can. People can handle bad news or frightening news if it's put into context for them and they believe it's accurate.<sup>1</sup>*

In an April 1 interview with NPR's "Morning Edition," retired U.S. Army Gen. Stanley A. McChrystal, former commander of U.S. forces in Iraq, explained that, in a crisis situation, accurate information from government authorities can be crucial in reassuring the public – and in the absence of accurate information, speculation and rumor will proliferate. Joni Mitchell, who's probably never before appeared in the same paragraph with Stanley McChrystal, might have put it a touch more poetically: "Don't it always seem to go; That you don't know what you've got 'til it's gone."<sup>2</sup>

The outbreak of the coronavirus strain COVID-19, which prompted the U.S. Department of Health and Human Services to declare a public health emergency on Jan. 31, 2020,<sup>3</sup> is introducing Americans to a newfound world of austerity and loss. Professional haircuts, sit-down restaurant meals and recreational plane flights increasingly seem like memories from a bygone golden age (small inconveniences, to be sure, alongside the suffering of thousands who've died and the families they've left behind).

<sup>1</sup> *How To Take A Leadership Role During A Crisis*, NPR MORNING EDITION, Apr. 1, 2020, <https://www.npr.org/2020/04/01/825056988/how-to-take-a-leadership-role-during-a-crisis>.

<sup>2</sup> Joni Mitchell, *Big Yellow Taxi*, on LADIES OF THE CANYON (Reprise Records 1970).

<sup>3</sup> Sara G. Miller & Erika Edwards, *HHS secretary declares coronavirus a public health emergency*, NBCNEWS.COM, Jan. 31, 2020, <https://www.nbcnews.com/health/health-news/u-s-declares-public-health-emergency-over-coronavirus-n1127856>.

Access to information from government agencies, too, is adapting to a mail-order, drive-through society. As public-health authorities reached consensus that the spread of COVID-19 could be contained only by eliminating non-essential travel and group gatherings, strict adherence to open-meeting and public-records laws became a casualty alongside salad bars and theme-park rides. Governors and legislatures relaxed, or entirely waived, compliance with statutes that require agencies to open their meetings to in-person public attendance and promptly fulfill requests for documents.<sup>4</sup>

As with all other areas of public life, some sacrifices in open-government formalities are unavoidable. With agencies down to a sustenance-level crew of essential workers, it's unrealistic to expect that decades-old paper documents will be speedily located and produced. And it's unsafe to invite people to congregate at public hearings to address their elected officials. But the public shouldn't be alone in the sacrifice.

Public officials can expedite fulfillment of requests for public records by relaxing some of their own review procedures. A not-insubstantial part of the delay that requesters experience when awaiting fulfillment of freedom-of-information requests is attributable to agencies parsing through dozens of non-mandatory exemptions to see how much can discretionarily be withheld.<sup>5</sup> For instance, nearly two dozen states mirror the federal Freedom of Information Act in allowing, but not requiring, agencies to discretionarily withhold "pre-decisional" records that reflect deliberations within the agency, the so-called "deliberative process" exemption.<sup>6</sup> Nothing requires agencies to conceal that category of records from the public. Concealment is a luxury option, not a necessity. Reviewing records to see which of them may – not must – be withheld from public disclosure is a textbook "non-essential" government function. Like other non-essential functions, it should be suspended as long as the state of emergency exists, so that the public receives everything but the records that, by law, cannot be disclosed.

### The power of public data

It's said that crisis brings out the best and the worst in people. COVID-19 has shown us unforgettably selfless acts of valor alongside ruthless price-gouging<sup>7</sup> and retaliatory discharges of whistleblowers.<sup>8</sup> The same might be said of government transparency.

We are witnessing the power of state and municipal "open data" portals to provide valuable datasets to an audience hungry for up-to-date, trustworthy facts. In recent years, more and more states and cities have created data dashboards that make high-value datasets accessible to the

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<sup>4</sup> For a rundown of the initial wave of state reactions, see Rachael Jones, *Open government in a WFH world: How public-records and open-meeting requirements are adapting to the COVID-19 threat*, MEDIUM.COM, <https://medium.com/@UFbrechnercenter/open-government-in-a-wfh-world-how-public-records-and-open-meeting-requirements-are-adapting-to-7d9c566db7ef>.

<sup>5</sup> For an explanation of the distinction between a mandatory versus discretionary public-records exemption, see Courtney Abshire, *Public Business is the Public's Business: Koch's Implications for Indiana's Access to Public Records Act*, 52 IND. L. REV. 455, 457-58 (2019).

<sup>6</sup> 5 U.S.C. § 552(b)(5) (allowing agencies to withhold "inter-agency or intra-agency memorandums or letters that would not be available by law to a party other than an agency in litigation with the agency").

<sup>7</sup> Jessica Guynn & Kelly Tyco, *Gouge Much? Purell for \$149, face masks for \$20: Coronavirus price hikes are making everyone mad*, USA TODAY, Mar. 3, 2020, <https://www.usatoday.com/story/money/2020/03/03/coronavirus-hand-sanitizer-face-masks-price-gouging-amazon-walmart-ebay/4933920002/>.

<sup>8</sup> Joe Garofoli, Tal Kopan & Matthias Gafni, *Navy captain of coronavirus-infected aircraft carrier relieved of command*, S.F. CHRONICLE, Apr. 2, 2020, <https://www.sfchronicle.com/bayarea/article/Navy-expected-to-relieve-captain-of-15175190.php>.

public, California’s Department of Health and Human Services maintains an online dashboard enabling visitors to see positive and suspected COVID-19 cases by county and by hospital location, as well as how many people are hospitalized in intensive care.<sup>9</sup> One of the most detailed is in Michigan, where the state provides a daily breakdown of cases by age, race and ethnicity, as well as the number of positive and negative test results.<sup>10</sup>

Journalists can add real value when they’re given access to the same data the government is working with. In Florida, reporters detected irregularities in the county-by-county tallies of COVID-19 cases, suggesting that the state health department may not be getting full and accurate reports from the counties.<sup>11</sup> *The New York Times* built an interactive worldwide map, updated daily, that helps people understand the spread of the pandemic and which countries have the most acute known problems.<sup>12</sup> This is the best of what technology, plus transparency, makes possible.

At the same time, we are witnessing the collapse of antiquated public-records systems in agencies from the FBI to Pennsylvania’s Department of Community and Economic Development to the San Diego health department, where officials have thrown up their hands and quit even trying to keep up with requests.<sup>13</sup> Agencies habitually shortchange spending on public-records compliance even in the flushest of times, creating slowdowns that are now becoming outright stoppages.

Since 1996, federal agencies have been required to affirmatively produce high-interest records in online “FOIA reading rooms” without requiring requesters to keep asking for them.<sup>14</sup> This isn’t, to be sure, a cure-all. Agency compliance is spotty; in 2015, the nonprofit National Security Archive looked at E-FOIA compliance at 165 federal agencies and found only 67 with updated online libraries.<sup>15</sup> And authorities can’t be trusted to disclose scandalous, self-incriminating records without being forced to. But it’s a start, and it’s better than what most state laws require.

Few states have matched E-FOIA’s affirmative-disclosure requirements, but the pandemic provides both an opportunity and a need to play catch-up. Agencies know, or should know, what records requesters most commonly ask for, and that’s doubly predictable today with Coronavirus-related stories monopolizing the news cycle. Research by the nonprofit Sunlight Foundation demonstrates that agencies can realize net savings by voluntarily posting documents online instead

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<sup>9</sup> Calif. Dept. of Health & Human Serv., *California COVID-19 Hospital Data and Case Statistics*, <https://data.chhs.ca.gov/dataset/california-covid-19-hospital-data-and-case-statistics>.

<sup>10</sup> Coronavirus: Michigan Data, Michigan.gov, [https://www.michigan.gov/coronavirus/0,9753,7-406-98163\\_98173--,00.html](https://www.michigan.gov/coronavirus/0,9753,7-406-98163_98173--,00.html).

<sup>11</sup> Diane Rado, *Coronavirus infections and death counts don’t always add up in FL*, FLORIDA PHOENIX, Apr. 2, 2020, <https://www.floridaphoenix.com/2020/04/02/coronavirus-infections-and-deaths-counts-dont-always-add-up-in-fl-data>.

<sup>12</sup> THE NEW YORK TIMES, *Coronavirus Map: Tracking the Global Outbreak*, <https://www.nytimes.com/interactive/2020/world/coronavirus-maps.html>.

<sup>13</sup> John Finnerty, *State dragging feet on releasing list of business waivers*, THE (SUNBURY, PA.) DAILY ITEM, Apr. 4, 2020, [https://www.dailyitem.com/news/state-dragging-feet-on-releasing-list-of-business-waivers/article\\_7956c73a-03ba-5194-8e40-c7b8947e605a.html](https://www.dailyitem.com/news/state-dragging-feet-on-releasing-list-of-business-waivers/article_7956c73a-03ba-5194-8e40-c7b8947e605a.html); JW August & Tom Jones, *Closed To The Public? Local Governments Respond Slowly – or Not at All – To Requests For COVID-19 Information and Records*, NBCSANDIEGO.COM, Mar. 31, 2020, <https://www.nbcsandiego.com/news/investigations/closed-to-the-public-local-governments-respond-slowly-or-not-at-all-to-requests-for-covid-19-information-and-records/2296678/>.

<sup>14</sup> See 5 U.S.C. § 552(a)(2)(D) (requiring federal agencies to publish any previously disclosed records that have been requested three or more times and are deemed likely to be the subject of future requests).

<sup>15</sup> National Security Archive, *Most Agencies Falling Short on Mandate for Online Records*, Mar. 13, 2015, <https://nsarchive2.gwu.edu/NSAEBB/NSAEBB505/>.

of incurring fulfillment costs to respond to repetitive freedom-of-information requests.<sup>16</sup> Never in modern history has it been more essential for agencies to allocate staffing resources economically, so voluntarily publishing plans, assessments, memos and correspondence relating to COVID-19 is not just good public policy; it's good business management.

### The myth of 'private statistics'

We're also reaping the consequences of badly drafted privacy statutes and regulations, as well as some fundamental "statistical illiteracy," that has resulted in some states, counties and cities withholding vital statistics about who's getting sick and where.

HIPAA, the Health Insurance Portability and Affordability Act of 1996, requires healthcare providers or insurers who transmit claims electronically for federal reimbursement to keep patients' identifiable medical records confidential.<sup>17</sup> Note all of the qualifiers in that definition: it applies to the release of identifiable patient information, gathered by a medical provider or insurer that does business with Medicare or Medicaid. Most significantly, once personal identifiers are removed from medical data, the data no longer qualifies as "protected health information" for HIPAA purposes.<sup>18</sup> That means, if the information is in a document or database that is subject to state public-records law, it must be disclosed on request.

Yet, HIPAA frequently is misunderstood – by agencies that plainly do not fit the statutory definition of a covered provider – to foreclose saying anything health-related. Any journalist who covers issues of health and public safety has at least one war story about a false-positive misinterpretation of HIPAA. The law has been (inaccurately) cited to conceal public records that refer to public officials' health,<sup>19</sup> to withhold the names of law-enforcement officers injured in the course of newsworthy events,<sup>20</sup> to conceal information about the deaths of people in custody,<sup>21</sup> and even to harass or jail journalists who take photos of medical emergencies.<sup>22</sup>

The federal Department of Health and Human Services, which administers and enforces HIPAA, did the public no favors in issuing recent interpretive guidance responding to questions about COVID-19.<sup>23</sup> In a February 2020 bulletin, HHS described the permissible contexts in which covered entities may disclose patients' confidential records – such as when sharing them with public-health agencies when necessary for public safety – but said nothing about what constitutes

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<sup>16</sup> Alena Stern, *Research: Cities can save time on records requests by doing open data right*, SUNLIGHT FOUNDATION, Oct. 9, 2018, <https://sunlightfoundation.com/2018/10/09/research-cities-save-time-on-records-requests-by-doing-open-data-right/>.

<sup>17</sup> 42 U.S.C. § 1320d-6(a)(3).

<sup>18</sup> See U.S. Dep't of Health & Human Serv., *OCR Privacy Brief, Summary of the HIPAA Privacy Rule*, <https://www.hhs.gov/sites/default/files/privacysummary.pdf> at 4 ("There are no restrictions on the use or disclosure of de-identified health information.").

<sup>19</sup> Jim Schutze, *Did Chief Hall Get Released From the Hospital or Just Climb Out a Window?*, DALLAS OBSERVER, July 22, 2019, <https://www.dallasobserver.com/news/where-has-dallas-police-chief-u-renee-hall-gone-11713590>.

<sup>20</sup> Scott Broden, *Inmate accused of assaulting Rutherford County jailer*, THE (MURFREESBORO) DAILY NEWS JOURNAL, Apr. 11, 2019, <https://www.dnj.com/story/news/2019/04/11/inmate-michael-wallace-duncan-accused-assaulting-officer-rutherford-county-jail-chris-fly/3434736002/>.

<sup>21</sup> Steve King, *Inmate dies at Guilford Co. Jail, cause under investigation*, WXII12.COM, May 4, 2018, <https://www.wxii12.com/article/inmate-dies-at-guilford-co-jail-cause-under-investigation/20190917>.

<sup>22</sup> Sam Tabachnick, *Denver officers disciplined for handcuffing journalist photographing arrest*, DENVER POST, Feb. 5, 2019, <https://www.denverpost.com/2019/02/05/denver-police-offers-discipline-handcuffing-journalist/>.

<sup>23</sup> U.S. Dept. of Health & Human Serv., Ofc. for Civil Rights, *HIPAA Privacy and Novel Coronavirus*, Feb. 2020, <https://www.hhs.gov/sites/default/files/february-2020-hipaa-and-novel-coronavirus.pdf>.

an individually identifiable record, or what must be done to make a record sufficiently de-identifiable to be made public. By failing to address that issue, HHS missed the opportunity to reassure state and county health departments that there will be no penalty for disclosing anonymized patient statistics and demographics.

Lacking authoritative federal guidance, state and local governments have reached diverging and irreconcilable interpretations of what data is and is not releasable. Florida Gov. Ron DeSantis cited patient privacy in refusing to name the nursing homes at which patients have tested positive for the virus; instead, the state is reporting aggregate numbers of confirmed infections and deaths in nursing homes statewide, a practice one advocate compared to a deadly game of Russian Roulette.<sup>24</sup> The same is true in Georgia, where the state Department of Public Health declined to identify the elder care homes where more than 50 COVID-19 cases were reported as of the start of April 2020, leaving journalists to piece the picture together by calling around to the owners of the facilities.<sup>25</sup> Other states, including Illinois and Maryland, have made the names of the institutions public.<sup>26</sup> In Massachusetts, the state has instructed municipalities to withhold the number of positive tests and deaths on privacy grounds,<sup>27</sup> even though neighboring Connecticut made the same information available online.<sup>28</sup> These states all are governed by the same federal privacy law. It cannot mean two different things.

Withholding statistics on privacy grounds is, at best, illogical. Confirmation that one, two, or twelve people in Brockton, Massachusetts, are hospitalized with Coronavirus does not enable anyone not already familiar with a patient's condition to deduce the patient's name. A person who suspects that her co-worker or neighbor might be sick with Coronavirus is no more able to confirm her suspicion from a numeral than she was without the numeral. That so many regulators in positions of authority are convinced otherwise speaks to a widespread cultural problem of "data illiteracy."

As many commentators have observed since the start of the COVID-19 outbreak, over-compliance with privacy laws is no longer just an inconvenient annoyance for journalists; it puts people at greater risk of harm. The editors of Raleigh's *News & Observer* took their state to task for being slow to reveal demographic information about COVID-19 patients, explaining that disclosure "can help improve understanding of the virus and its spread among North Carolinians,

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<sup>24</sup> Carol Marbin Miller, *Like playing 'Russian roulette': DeSantis won't say which elder care homes have coronavirus*, MIAMI HERALD, Mar. 25, 2020, <https://amp.miamiherald.com/news/coronavirus/article241487396.html>; Rafael Olmeda, Florida continues to conceal the names of senior facilities with coronavirus, THE (FORT LAUDERDALE) SUN-SENTINEL, Mar. 31, 2020, <https://www.sun-sentinel.com/local/palm-beach/fl-ne-nursing-home-coronavirus-secrecy-20200331-5ars2ak7r5g4pozx3uu5mqzarm-story.html>.

<sup>25</sup> Brad Schrade & Carrie Teegardin, *Coronavirus cases now reported at 58 Georgia senior care facilities*, Apr. 2, 2020, ATLANTA JOURNAL-CONSTITUTION, <https://www.ajc.com/news/state--regional-govt--politics/coronavirus-cases-now-reported-georgia-senior-care-facilities/BRPt7AIobRRAYKvw3SF6aJ/>.

<sup>26</sup> Madeline Buckley, *2 more nursing home residents die after contracting COVID-19 as DuPage County cases surpass 600*, CHICAGO TRIBUNE, Apr. 4, 2020, <https://www.chicagotribune.com/coronavirus/ct-coronavirus-illinois-dupage-deaths-nursing-homes-20200404-bckmjn3m6bgi3kvjpvrmnfgc64-story.html>; Matthew Stabley, *9 Residents Dead in COVID-19 Outbreak at Maryland Nursing Home*, NBCWASHINGTON.COM, Apr. 4, 2020, <https://www.nbcwashington.com/news/local/9-residents-dead-in-covid-19-outbreak-at-maryland-nursing-home/2264528/>.

<sup>27</sup> Cody Shepard, *Massachusetts DPH asks cities, towns not to release coronavirus numbers*, THE (BROCKTON) ENTERPRISE, Mar. 28, 2020, <https://www.enterpriseneeds.com/news/20200328/massachusetts-dph-asks-cities-towns-not-to-release-coronavirus-numbers>.

<sup>28</sup> See *Coronavirus Disease 2019 (COVID-19)*, CT.gov, <https://portal.ct.gov/Coronavirus>, at 10 (providing daily chart of location, by town, of positive test results).



and it can accentuate issues and dispel myths that contribute to that spread.”<sup>29</sup> The *Baltimore Sun* called for tracking and publishing CORVID-19 deaths by race, as Michigan has begun doing, so public-health professionals can more intelligently target prevention and response efforts to those most in need.<sup>30</sup>

When federal regulators become aware that privacy laws are causing confusion, they should act to dispel the confusion -- and when the information is a time-urgent as the number and location of life-threatening infectious diseases, they should act with urgency. Federal privacy laws do not take adequate account of the public interest in access to information embodied in the 50 state open-records statutes. Exceptions to disclosure are always supposed to be construed narrowly with a presumption in favor of public access,<sup>31</sup> and HIPAA is no different. If state and local authorities find HIPAA’s privacy constraints too confining and too confusing, Congress can act with the same dispatch that saw \$2 trillion in relief aid approved in a matter of days.<sup>32</sup>

## Conclusion

At a time when prompt access to accurate information could literally mean the difference between life and death, the laws mandating disclosure of information to the public are being relaxed in the name of government efficiency, while those mandating secrecy are being applied rigidly (and at times, inaccurately over-applied). This isn’t just a problem for journalists and researchers. As Harvard University health-law professor I. Glenn Cohen told *The New York Times*: “Public health depends a lot on public trust. If the public feels as though they are being misled or misinformed their willingness to make sacrifices – in this case social distancing – is reduced.”<sup>33</sup> Perhaps the lasting legacy of the COVID-19 pandemic – and it will be a relief to speak of the pandemic in the past tense – will be a generational recommitment to restore custody of critical health-and-safety information to its rightful public owners.

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<sup>29</sup> Editorial: *There’s a lot you can learn about coronavirus in other states that you can’t in North Carolina*, THE (RALEIGH) NEWS & OBSERVER, Mar. 27, 2020, <https://www.newsobserver.com/opinion/editorials/article241555071.html>.

<sup>30</sup> Commentary: *Coronavirus deaths should be tracked by race*, BALTIMORE SUN, Apr. 3, 2020, <https://www.baltimoresun.com/opinion/editorial/bs-ed-0403-coronavirus-race-disparity-20200403-npngxilobfa2hm3aishcwuj6ui-story.html>.

<sup>31</sup> See, e.g., Office of Gov. v. Scolforo, 65 A.3d 1095, 1100 (Pa. Commonw. 2013) (“Exemptions from disclosure must be narrowly construed”); Daniels v. City of Commerce City, 988 P. 2d 648, 650 (Colo. App. 1999) (“Exceptions to the [Open Records] Act should be narrowly construed.”).

<sup>32</sup> Eric Wasson & Billy House, House Approves \$2 Trillion Virus Relief Bill, Sends to Trump, BLOOMBERG NEWS, Mar. 27, 2020, <https://www.bloomberg.com/news/articles/2020-03-27/house-approves-2-trillion-virus-relief-bill-sends-to-trump>.

<sup>33</sup> Thomas Fuller, *How Much Should the Public Know About Who Has the Coronavirus?*, THE NEW YORK TIMES, Mar. 8, 2020, <https://www.nytimes.com/2020/03/28/us/coronavirus-data-privacy.html>.