Diagnostic Citizenship
And the biopolitical uptake of COVID-19 detection

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Abstract

This essay examines an oddity of SARS-CoV-2 diagnostic testing—referred to here as a ‘persistent positive’—in which an individual can test positive for COVID-19 for weeks or even months after initial infection despite no longer being symptomatic or contagious. In Florida, where recent legislation requires healthcare workers affected by COVID-19 to have two negative test results before they can return to work, the issue of persistent positives poses a significant challenge for a small sub-group. I identify an important disconnect between the biological and the biopolitical where SARS-CoV-2 test results are mis-inscribed into biopolitics as bureaucratic state legal codes and employment requirements. Using ethnographic evidence, I show how their test results are less important than the state’s interpretation and enactment of these test results. I describe a technopolitical phenomenon wherein the technical (in this case diagnostic testing) selectively offers up rights to those recovering from COVID-19. Those with persistent positives performatively engage in testing as a means of navigating the legal codes that deny them the right to work. Testing for them is an attempt to return to a normal life, not to find out whether they are living an abnormal one. A breed of biological citizenship, perhaps a diagnostic citizenship, is formed in which they need a certain result, no matter what that result means biologically, in order to exercise certain rights. These reflections encourage a rethink about the role of testing technology as an instrument of government and biomedical authority more broadly.

Keywords

COVID-19, Biopolitics, Testing, Diagnosis, Florida.
'I’m sick of this shit,' the woman said over the phone. ‘How long is my daughter going to test positive for?’ It was early morning, and I’d not recognised the number when her call came in. She spoke with a thick Jersey accent and was openly frustrated, demanding answers about her daughter’s SARS-CoV-2 test results. I was working with the Florida Department of Health (FL DOH) on COVID-19 at the time, contracted in a technical capacity and not working with any particular ethnographic intent, and most of my days were spent contact tracing. I carried out interviews with those who tested positive for the virus—referred to as ‘cases’—and identified any close contacts the individual may have exposed. Anyone exposed would be rapidly notified, asked to quarantine, and have their symptoms monitored over the following two weeks. Rarely did I get unsolicited calls like this. I had not spoken to the woman previously and did not know how she had gotten my number. It is hard to find direct office lines for FL DOH employees. If I called people from my office phone and they called the same number back, it would send them to the general COVID-19 call centre for FL county. Either someone had unknowingly given her my extension code or she’d been guessing phone numbers. She was clearly concerned, however, so I did not question it. Without even telling me her name, she began raging about all the tests her daughter had to do and ‘how far they stick that damn swab up your nose’.

As she spoke, I minimised an Excel spreadsheet of the county’s latest epidemiological data. Behind it was the state’s daily COVID-19 report and the FL DOH’s repository for all communicable disease data, called Merlin. I pushed aside the county map on the desk in front of me and replaced it with a copy of the department’s contact tracing guidelines, an up-to-date list of clinics and centres in the area with testing availability, and a roster of phone numbers for all the local hospitals’ infectious disease units. To my side, I kept a printout of the four-page contact tracing form provided by the state to guide conversation. The form covers demographic information; symptoms; and any treatment, risk factors, close contacts, and testing history. There is a small space at the bottom of the last page for any other notes.

When ready, I turned my chair back towards the landline phone on the corner of my desk and interrupted: ‘Could you give me your daughter’s name? Yours too, please. We should have you both in the system.’ All information on Florida’s COVID-19 cases are in the Merlin data system. If her daughter had tested positive, her details would be there. ‘Her name is Sabrina Ross. R-O-S-S. That’s my daughter.’ She paused for a moment. ‘And I’m Linda Neumann. N-E-U-M-A-N-N.’

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1 All names in this piece are pseudonyms used to protect anonymity. The vignette that grounds this article blends the experiences of several people with whom I spoke during my time at the FL DOH between April and August 2020. The experiences were strategically chosen and organised to ensure no single person could be identified, but also to ensure that the presented account accurately reflects the ethnographic data.
Linda had tested negative and never fallen ill, so I loaded Sabrina’s profile first. As she continued on about her daughter needing to return to work, I quickly sifted through a number of drop-down menus and read through the case notes written by a colleague who had previously spoken with Sabrina:

21 YR OLD.
NO KNOWN EXPOSURES OR TRAVEL.
NO UNDERLYING CONDITIONS.
TESTED + ON 3/5/20.
SOB. DRY COUGH. 100.4 FEVER.
SX ENDED 3/6/20.
SHARED HH WITH MOTHER LINDA NEUMANN #0784491, NO SX, - TEST ON 3/5/20.

Over time, I’d adopted my colleagues’ practices and learned the written shortcuts for the most common words and phrases: ‘SOB’ for ‘shortness of breath’, ‘SX’ for ‘symptoms’, ‘HH’ for ‘household’, ‘VM’ for ‘voicemail’, ‘CB’ for ‘call back’, ‘CHD’ for county health department, ‘LTCF’ for ‘long-term care facility’, ‘+’ for positive test, ‘-’ for negative test, and so on. Presented alone, this internal language paints quite an accurate picture of contact tracing and the most common topics of conversation at the department.

Sabrina had had a mild case of COVID-19. Her symptoms had lasted just three days and, at the time Linda called, six weeks had passed since their onset. During those six weeks, she had tested positive two additional times and, on the day Linda called, had just got her fourth test result: another positive. Testing positive, however, was not as much of a problem as it first appeared; in fact, ‘COVID-positive’ can be a rather misleading metric. Once swabs are taken for testing, a machine detects fragments of the virus’s RNA in the sample. This tells lab staff whether the genetic material is present—and that’s all. We incorrectly conflate the presence of the virus’s RNA with the presence of a virus capable of spreading. The way to tell if someone is actually contagious is to see if the sample can be cultured in the laboratory. If so, the virus can replicate and spread. With COVID-19, viral debris or leftover RNA fragments can shed for extended periods after illness and be detected but not cultured. Data suggests that mild COVID-19 cases are contagious for just around ten days.

The guidelines used at the FL DOH were in line with this data. If symptomatic, the case ends isolation ten days after symptom onset and 72 hours after the symptoms

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2 The case notes included in this article are not real case notes but do accurately reflect the note-taking system used internally.
resolve. If asymptomatic, the case ends isolation ten days after the first positive test. As such, Sabrina should already have been back at work. I was admittedly confused, but then saw ‘HCW’ (our internal abbreviation for ‘healthcare workers’) in the last line of her case notes. I immediately knew the problem—it was one I had seen a number of times in my short tenure with the FL DOH.

Early in the pandemic, Florida Governor Ron DeSantis signed a law mandating that all infected healthcare workers had to have two negative tests before returning to work. The ruling took precedence over the aforementioned clearance strategies and was a response to the concerning spread of COVID-19 in Florida’s nursing homes. As an indirect result of this ruling, I spent a lot of time discussing testing availability and results with healthcare workers who were out of work due to COVID-19. Among these healthcare workers, I encountered a small but significant number of people who had tested positive for weeks on end—a phenomenon I came to call a ‘persistent positive’. These individuals, despite being neither ill nor contagious, were barred from returning to work for extended periods of time and suffered a range of consequences as a result. Sabrina, too, was subject to this legal code.

The issue in such cases is not a lack of biological clarity; biologists and public health researchers fully understand the possibility for these persistent positives. The problem is instead the perceived authority of the diagnostic test as the ultimate arbiter on safety, greater even than the same researchers who created the test and recognise its shortcomings. Significantly, we call it a diagnostic test and not a detection test. ‘Diagnosis’ implies a clinical condition and often contagion, whereas ‘detection’ implies a mere biophysical presence. Biology warns us about the possibility of persistent positives; it is not the problem. Rather, the problem arises when biology is mis-inscribed into biopolitics; that is, when those in power register detection as diagnosis and rework social life around a positive test result no matter its meaning.

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‘Can you tell me about your situation?’ I asked Linda, hoping to get additional contextual information before offering help. In alignment with the case notes, Linda mentioned her daughter’s symptoms from several weeks ago and listed specific dates for all her tests. She had every detail written down. ‘We have been so responsible, but I just need to get Sabrina out of the back room,’ she pleaded. Her daughter had been isolated in a room of their home for the preceding 41 days. Mostly used for storage, the room was stacked with boxes and had only one small window. Sabrina refused to come out as she did not want to infect her mom. For every meal, Linda left food on the ground outside of Sabrina’s door and used disposable plates, silverware, and napkins. Linda would then get as far away from
the room as possible and, after a few minutes, Sabrina crept open the door, grabbed her food, and slammed it shut again. She had a trashcan in the room, and they took it out every few days. Sabrina would tie up the bag and place it outside the door. After some time, Linda would put on masks and gloves, aggressively spray the bag with disinfectant, and carry it to the curb. She was just as scared as Sabrina and reiterated how bad she felt for her daughter: ‘Sabrina isn’t even able to pet the dog!’ Once back to normal, Linda and Sabrina planned to leave the room untouched for three weeks and then throw away all the bedsheets and pillows. First, though, they needed two negative tests. 'How long is my daughter going to test positive for?' she repeated. 'I just want to hug her.'

No one wants to be told they could test positive for weeks or even months, especially a healthcare worker whose ability to work depends on it. I cautiously explained the persistent positive phenomenon and how that seemed to explain Sabrina’s situation. I told her that a positive test does not necessarily mean a person is contagious, calling into question by doing so the logic grounding Florida’s legislation. It was beyond my role to do this and, from brief conversations with my colleagues, I gleaned that not everyone at the FL DOH knew about the trend of persistent positives seen throughout the world. Yet even as I explained this oddity, there was little I could actually do for Linda and Sabrina given the institutional structures to which I was bound. Positive meant bad and, as an FL DOH employee, I was expected to uphold this interpretation in my daily work. Managing tensions—between bureaucratic procedures, frustrated people, and changing situations we did not know much about—was simply part of the job.

I let Linda know that Sabrina would be fine to leave the back room, but she hesitated. The testing apparatus intended to help had instead produced a particular imaginary of contagion that was shaping social life for both of them. Sabrina felt like a carrier of a new virus that conjured up frightening images of intubated patients and overrun hospitals, and did not want to infect anyone around her, least of all her mother. Linda and I deliberated for the next few minutes. I spent most of this time assuaging her concerns, but she eventually reached a conclusion of her own: Sabrina could leave the room and sit on one of the couches in the living room. Linda would sit on the other couch, which she emphasised was over six feet away. They would watch TV together. Linda would also give her one quick hug, both wearing masks, and change her clothes and spray disinfectant on herself after. I reminded her that she would not have to be that strict, that Sabrina wasn’t contagious anymore, but Linda said only that she would think it through. We scrupulously analysed the mechanics of prospective social interaction in Linda’s living room.
In the meantime, she asked that I organise another at-home test for Sabrina. Testing was a way for Sabrina to navigate the bureaucracy and legal codes that restricted her. She despised being tested, but knew it was the one way for her to reclaim her right to work. It was indeed a performance, and I was the audience. Linda knew that I, an employee at the FL DOH, was one of the few people who could help her daughter get out of the bind she found herself in. I was the one who provided all the details of testing availability, and I would ultimately be the one to write her work-release letter. This naturally shaped the conversations we had. As this anecdote illustrates, contact tracing is much more than a neutral information request; It is an active negotiation of daily realities, a stage upon which certain experiences can be presented, and an act of compliance with the technocrats who dictate Sabrina’s—and others’—movements.

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Over the next few days, Linda and I spoke several times. During one call, she told me how she used a tape measure to separate the couches by exactly six feet. During another, she said the dog jumped on Sabrina’s couch and that she screamed when it happened. Linda stopped touching the dog. Sometimes we spoke over the phone as she ordered General Tso’s chicken from the local deli or a drink from McDonald’s. She integrated calls to the health department into her daily routine (usually she’d call to check for test results, ask for a retest, or share any other updates she deemed relevant). ‘I can just call Cindy if I don’t hear from you,’ she would say. It was clear that alongside her recorded testing dates, she had also noted a list of FL DOH numbers. ‘I called like a thousand people to get Sabrina tested,’ she once told me. ‘I called you, Priya, Ryan, Cindy, and Devon.’ I didn’t even know someone named Devon at my workplace—but Linda did. She became an expert at navigating bureaucracy, because that was all she could do. The only way out of this quandary was two negative tests.

One day, I arrived at the office to find three missed calls and three separate voicemails from Linda. I returned her call. She said that she was now unable to return to work. Her employer, a daycare centre, had asked her to not return until her daughter tested negative. Even though Linda had tested negative and all necessary precautions had been taken during Sabrina’s illness, the new workplace policy was enforced. As is clear, these biopolitical mis-inscriptions of the SARS-CoV-2 test happen not only at the level of the state but also of private business. Everyone in the household was out of a job, and finances were becoming a creeping concern. The pandemic reworked the local economy in countless ways—Sabrina and Linda’s restricted participation is just one example.

On this same call, Linda said that Sabrina was back in her room. She had a headache and ear itch, and refused to come back to the couch. She did not, she
said, want to infect her mother. But after learning that Sabrina commonly has headaches, I let Linda know that it should not be a concern and that itchiness is not a known symptom of COVID-19. We talked it through for a bit, and Linda decided ‘the headache is from dealing with all this bullshit’. She laughed and explained how hard it was to find a testing site where she fit the testing criteria and would not have to spend money, drive a long distance, stand in line for hours, worry about the site running out of tests, and/or wait several days for the result. Additionally, Linda could not go to a site that required a self-swab; she did not trust herself to stick the swab deep enough into her nose and wanted a clinician to do it. All these specifics changed weekly, and testing sites closed and relocated just as fast. Linda was absolutely correct: getting tested was a headache.

Eventually, more than two months after Sabrina’s symptoms resolved, I let Linda know her fifth and sixth tests were both negative. She squealed and said, ‘I can hug her now!’ I offered to write work-release letters for both Linda and her daughter, and we spent the next few minutes celebrating over the phone. They were overjoyed and relieved to finally be done with the ‘testing mess’, as Linda called it. When we finished our final call, I heard Linda yell ‘Yaaaay, Sabrina!’ before hanging up. They were free to go.

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There were many cases of persistent positives I observed, each one different from the last. One man started laughing when I told him he’d tested positive for the fifth time, thinking it was all a joke at this point. Another woman applied for a new job as she was not able to provide for herself or her family. Yet, despite their differences, everyone I spoke to was affected by the same issue: a disconnect between the biological and the biopolitical, wherein SARS-CoV-2 test results are mis-inscribed into biopolitics as bureaucratic state legal codes and employer requirements. For Sabrina and many others, test results are less important than the interpretation and enactment of those test results.

In this way, the problem of persistent positives is socially and technically engineered, not biologically. Biology says those experiencing persistent positives are non-infectious and safe to return to work, but the biopolitical takes precedence. I describe a techno-political phenomenon wherein the technical—that is, diagnostic testing—only selectively offers up rights to those recovering from COVID-19. People with persistent positives performatively engage in testing as a means of navigating the laws that deny them the right to work. Testing, for them, is an attempt to return to a normal life, not to find out whether they are living an abnormal one.
A breed of biological citizenship, perhaps a *diagnostic citizenship*, is formed in which certain people need a certain result, no matter what the result means biologically, to exercise certain rights (Petryna 2002). To fully realise this citizenship, they engage in a sort of calculus to find their way out of the testing problem: strategically navigating bureaucracy, constantly searching for testing sites, and repeatedly testing as a means of reclaiming their right to work. The phenomenon of persistent positives prompts a rethink of how the pandemic reorients citizenship projects around biological knowledge, numbers, and diagnostics. It foregrounds the importance of conversation about the political economies of testing technology in the COVID-19 era. In exploring these questions, we learn more about how access to rights and resources are centred around biological claims and the limits of testing technologies as instruments of government.

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References