Caught Between Civil Liberties and Public Safety Fears: Personal Reflections from a Healthcare Provider Treating Ebola

Kaci Hickox*

Imagine reading a hypothetical affidavit that begins something like this:

Only 24-hours ago I was on a plane with the giddy anticipation of visiting one of my best friends in New York City. Soon after I awaited a tender, enveloping, sigh-of-relief hug from my partner, Ted, in Maine. I longed for these simple yet cathartic moments because for the past five weeks I had been treating Ebola patients in Sierra Leone. Instead, it is Saturday and last night I was quarantined in a tent in Newark, New Jersey. My temperature, heart rate, and blood pressure are normal. I have no signs or symptoms of Ebola.

I feel like I could run a marathon but my heart is aching. My eyes betray me as I try to hold back tears. I must remain strong, but I feel betrayed and alone. They tested me for Ebola last night even though I did not meet any criteria that would merit such a test. Although I tested negative for Ebola, there is no sign I will be able to leave this plastic prison-tent. The doctors, nurses, and paramedics taking care of me are kind, but they do not appear to be advocating for me. They are merely doing what they are told. I remind myself to take a deep breath, and then another. I am alone in a tent. I am healthy with no symptoms of Ebola, yet I have been told no one can come and see me through the plastic windows of the tent.

I know I cannot give anyone Ebola because I do not have symptoms. My rights have been taken away as if they do not matter and the wrong people are making the decisions, people without expertise in public health or medicine. I lay in bed and cry because I am exhausted and alone but I cannot fall asleep. Finally, I stop trying to sleep and call Ted at 4 a.m. He is awake, unable to sleep either. He tells me, “I just want you to be at home so I know that you are safe.”

* Kaci Lynne Hickox, MSN/MPH, BSN, RN. Hickox holds a dual master’s degree in public health and nursing from Johns Hopkins University. Hickox also received a Diploma in Tropical Nursing from the London School of Hygiene and Tropical Medicine. Hickox is currently working as a clinical nurse educator in Oregon.
Two days ago an aid worker returning from West Africa was the first to develop symptoms and test positive for Ebola on U.S. soil. I am being held captive in a tent due to fear and politics. Science and public health principles are being ignored and I am being used to make Governor Chris Christie appear presidential. Some of the U.S. public agrees with his actions due to fear and manipulation. What scares me the most is a thought that plays like a broken movie reel in my head—what if they keep me here, alone in this tent, for the entire twenty-one days?

These events led me to fight against my involuntary quarantine in a tent in New Jersey and then against an involuntary home-quarantine in my home state of Maine. As I reflect back on my initial decision to contest these policies for my constitutionally protected rights, I come to one resounding reason as to why: I was terrified of the people who were taking away my rights and what they would do to other healthcare workers if they were not held accountable for their actions.

I. Mid-Term Election Politics and Fear

When I left to help treat those affected by the Ebola outbreak I never imagined returning to the situation in which I found myself. I knew that people all over the world, including myself, had a healthy fear of Ebola. This fear can be productive as it requires strict attention to monitoring and infection control guidelines, which minimize the spread of infection.

Upon my arrival in Bo, Sierra Leone, I was immediately comforted by my colleagues in the Bandajuma Ebola Management Center ("BEMC"). The BEMC leaders trained all clinicians on strict infection control protocols, and ensured that such protocols were continuously followed. As part of our training, the BEMC psychologist reminded us that it was normal to feel anxious in the face of Ebola, but that we must trust each other and the multiple layers of protection in place. Furthermore, we should monitor ourselves by taking our temperatures twice a day or if we felt ill, but further monitoring was unnecessary.

On my second day at BEMC, the nurse in charge of the clinic told me that I must think with my head when treating Ebola patients. She added that good judgment may save my own life as well as my colleagues’ lives. I began to understand what she meant as I watched patients in the unit who were too weak to sit up on their own. These patients had to wait for us to put on our personal protective equipment ("PPE") before we could help them. I once watched through the fence that separated us from the patients as a female patient fell. There was nothing I could do because I was not in PPE. She would have to wait until the next medical team going into the patient area
could help her. I felt both angry and thankful for the PPE, knowing that it protected me but also hindered my ability to care for those suffering.

Sadly, when the United States public needed leadership and a clear evidence-based public health message about Ebola, some politicians chose to lead a fear campaign in hopes of winning mid-term elections. Governor Chris Christie of New Jersey made it clear during media interviews that he was not interested in listening to the experts who pressed him to release me from quarantine.\(^2\) He was also comfortable misspeaking about my medical condition when it helped him in scaring the people of New Jersey, saying in an interview, "She . . . is obviously ill."\(^3\) He made this false statement without medical expertise and in complete disregard to my right to the privacy of my medical information.

You can imagine my horror when my mother called me in a panic asking, "Is it true, honey? Are you sick?" I was not sick. My Ebola test was negative. I had no symptoms of Ebola. Governor Christie used me to falsely promote public fear, implement unlawful and unnecessary policies, all while proclaiming to be protecting the public. But Governor Christie did not care about me, my rights, or protecting the public from an infectious disease. He chose to play politics instead of being the leader we needed.

Governor Paul LePage of Maine played the same game. I often wonder, what would have happened if he had instead met me on my journey from New Jersey at the Maine state line and gave me a big hug to welcome me home?\(^4\) How would Americans have reacted if Governor LePage chose to model what an evidence-based, compassionate reaction to returning Ebola healthcare workers looked like? Instead, Maine implemented a policy requiring all healthcare workers returning from Ebola-affected areas to home-quarantine.\(^4\) He made accusatory statements to manipulate the

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public saying about me, “I don’t trust her.”

During our negotiations, Governor LePage told my lawyers and the press that I could be free of quarantine if I would submit to another blood test for Ebola, a comment that his office quickly retracted. It made no medical sense because the test for Ebola is not accurate unless an individual is showing symptoms of the disease. The United States Center for Disease Control (“CDC”) would likely not have agreed to perform the test on my blood because I was still asymptomatic. Governors LePage and Christie showed poor judgment, a lack of leadership, and they missed an opportunity to support public health experts and reduce stigma and fear so that we could respond to the Ebola outbreak with the human resources so desperately needed.

II. A Civil Rights Lawyer on Speed Dial

When I arrived back in the United States, I believed appropriate public health measures would be applied to me and others upon our returns. It was just a few hours after I called Ted early Saturday morning from the quarantine when he encouraged me to contact the American Civil Liberties Union (“ACLU”) or a lawyer. Through friends I had met at Johns Hopkins University, I dialed the number of respected civil rights attorney Norman Siegel. I realized that science was not going to prevail without someone taking a stand and I needed legal support in order to fight against a violation of my civil rights and the politicians making these decisions.

When Norman Siegel answered the phone that Saturday I remember saying these surreal words, “Hello, this is Kaci Hickox, the nurse who is quarantined in New Jersey.” Siegel paused and with a sincerity and warmth that I did not expect from a Disease Control and Prevention).


prominent New York City lawyer he replied, “Kaci, how are you doing?” He was not all business and he did not dive straight into the legal issue at hand. He displayed an innate understanding of humanity and looking back I realize that this is what I needed even more than legal expertise. I failed at holding back the tears as I replied that I was trying to be strong, but I felt so scared and alone. I had only been in the tent for one night, but it was emotionally exhausting and isolating. I continued to describe what I was going through to Siegel. I could not sleep well in the tent. It was cold, the hospital bed was uncomfortable, and most of all I was alone. I always understood from an intellectual standpoint that isolating Ebola patients must be emotionally crushing, but now I was experiencing it myself. Although I took solace in knowing that I did not have Ebola, that knowledge made my forced isolation all the more frustrating. The medical staff would come into the tent to take my vital signs or clean the portable toilet every six hours. Sometimes they would have me take my own temperature, blood pressure, and heart rate so they did not have to come inside the tent. I asked if Ted could come and see me through the plastic window. This made sense because the hospital workers were standing and chatting with me in normal clothes on the other side of the windows. I was told no, the New Jersey Department of Health would not allow visitors to see me. There was no way for me to look into the eyes of my loved ones. I could disappear and no one would know where I had been or how I was being treated. Finally, Siegel and his co-counsel, Steve Hyman, insisted on meeting with me and we talked through the plastic window of the tent on Sunday evening.

III. From New Jersey to Maine: Tent to Home-Quarantine

It was not until Monday morning, three days after testing negative and exhibiting no symptoms of Ebola, that I was finally released from the quarantine tent in New Jersey. I sat outside of the tent within the building in which the tent was held for several hours. The healthcare workers, administrators, and security guards stood around waiting for me to leave. We chatted and shook hands, everyone in their normal clothes or scrubs and no one appearing to be worried about Ebola.

I returned to Maine in a black SUV with three emergency medical technicians (“EMTs”) from New Jersey who wore normal clothes and no protection. We drove for seven hours through New Jersey, New York, Massachusetts, Connecticut, and New Hampshire, stopping at several gas stations for bathroom breaks before reaching Maine. What about local quarantine laws in these states? Why would New Jersey be willing to put their EMTs and much of New England at risk? These inconsistencies point to the fact that those making the decisions understood that I did not pose a risk to anyone. Similarly, no one had recommended that American healthcare workers returning from
treated from traveling home on international commercial flights. Passengers on my flight from Brussels to New Jersey were not notified or monitored for Ebola. If those in power believed quarantine was necessary in order to protect the public, policies would be consistent and logical. Unfortunately, Ebola policies had become political.

I arrived to southern Maine around eight o'clock in the evening, thankful to finally be in the arms of my partner. My excitement quickly turned to frustration as the Director of the Maine CDC explained to me that Maine would require home-quarantines for all healthcare workers returning from Ebola affected areas, regardless of their health status or exposure assessment. I later learned the Maine CDC protocol was signed on October 27, 2014, the day I arrived in the state.9

My partner and I arrived at our home in Fort Kent, Maine the next day around eleven at night, finding a state trooper parked across the street of our house. Governor LePage stated that the state trooper was “for [Kaci’s] protection,” another exaggeration.10 As soon as a Maine judge ruled in my favor and against the state’s request for a home-quarantine order, the state trooper drove away and my ‘protection’ was no longer the governor’s concern.

IV. Transparency and Due Process

I have been told that our bike ride was seen around the world, maybe second in notoriety only to the Tour de France. Aside from allowing us to get some much needed fresh air, we rode our bikes out of strategic necessity. As I was not sick, I was not going to submit to voluntary quarantine and the state of Maine requires a court order to place someone under quarantine. Like many states, Maine hoped that Ebola workers would sit quietly and simply follow the state’s request.

The bike ride forced Maine’s Department of Health and Human Services to file a court order for my home-quarantine and to present their allegations that I was a public health threat.11 This evidence was analyzed by a judge and weighed against my due

9 See supra note 4 and accompanying text (detailing Maine CDC protocol).
11 See ME. REV. STAT. tit. 22, § 812 (2014) (requiring treatment for individual deemed by court to be a public health threat); Verified Petition for Public Health Order at 5-6, Mayhew v. Hickox,
process rights under the Fourteenth Amendment.\textsuperscript{12} States can request a voluntary quarantine of an individual, as Maine initially did with me, though the legal precedent for involuntary quarantine varies among states. For example, Maine requires a court order whereas some states allow a state health officer to enact mandatory quarantine through a public health order.\textsuperscript{13}

It was only after our bike ride that the State of Maine Department of Health and Humans Services obtained a temporary court order for my home-quarantine. Attorneys Norman Siegel and Steve Hyman, along with my local counsel David Soley, challenged this temporary order on the grounds that I was not a public health threat. On October 31, 2014, Judge Charles LaVerdiere of the Maine district court ruled that the state had not met their burden of proof, which was to show that I was a public health threat. Judge LaVerdiere correctly stated, “the State has not met its burden at this time to prove by clear and convincing evidence that limiting [Hickox’s] movements to the degree requested [home-quarantine] is ‘necessary to protect other individuals from the dangers of infection.’”\textsuperscript{14} I remain thankful and encouraged by our court system, which succeeded in upholding my civil rights in the midst of fear and chaos. However, I remain very concerned by the political stunts of Governor Christie, a man considering a presidential run, and Governor LePage. We must do more to ensure state governments are using their powers appropriately based on the actual needs of the public and are not disproportionately regulating.

V. Model for Balancing Individual Rights and the Public’s Health

The use of quarantine is an important public health measure that should be used with extreme care. Medical science and public health principles must be carefully considered and the least restrictive means necessary should be placed on an individual to prevent the spread of an infectious disease. I am afraid that even after all of the media attention concerning Ebola and quarantine, most Americans do not understand the rigorous scientific and legal model that should be applied when considering a public health action as extreme as quarantine.

\textsuperscript{12} U. S. CONST. amend XIV, § 1 (prohibiting states from denying individuals’ life, liberty or property without due process).
\textsuperscript{13} Compare ME. REV. STAT. tit. 22, § 812 (2014) with ALA. CODE § 22-3-8 (2014) (authorizing appointment of county quarantine officer to perform duties related to quarantine).
As I spoke to representatives of the New Jersey and Maine health departments, I explained these principles time and time again. Why should I be quarantined if I did not pose a risk to the public? Why should I be required to stay in my home if I was not ill and thus not able to spread disease? Why would they choose such extreme measures when Ebola is not highly infectious in the initial days of symptoms, unlike diseases such as measles and influenza? The officials had one of two answers: “This decision was not made by me, but at a higher level” or “You have to understand that we are trying to allay the fears of the general public.” Sadly, neither of these two answers addresses the legal standard to order an involuntary quarantine of an individual with an infectious disease.

Here are the questions that I believe must be asked by medical and public health professionals when quarantine is being considered:

**Does the individual pose a risk to the public?** In the case of asymptomatic healthcare workers returning from treating Ebola patients, the answer is no. Digging deeper, we ask the following questions:

**Is the individual infectious or was he or she exposed to an infectious disease?** A person with Ebola is not infectious until showing symptoms. A person exposed to Ebola and showing symptoms could be infectious and should be isolated and tested. A person who is asymptomatic is not infectious. Furthermore, not all healthcare workers caring for Ebola patients have been exposed.

**What is the likelihood the individual will develop disease?** At the end of October 2014, Doctors Without Borders reported over 3,300 staffers or volunteers working in West Africa as part of the Ebola response; twenty-three developed Ebola.

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16 See Upshur, supra note 15.

17 See Upshur, supra note 15.

18 See Upshur, supra note 15.

Of the three international staff who developed Ebola, one developed Ebola symptoms after he arrived in his home country and the other two developed symptoms while working in West Africa. In light of these numbers, recommending home-quarantine would negatively impact hundreds of workers who will never develop Ebola.

What is the likelihood that the individual will infect others? Ebola is not very contagious during the initial stages of the virus. Therefore, during the early stages, it is unlikely that an individual with Ebola in the United States would infect others in his or her community. Consider Dr. Craig Spencer and nurses Nina Pham and Amber Vinson. They were all diagnosed with Ebola in the United States yet none transmitted Ebola to their household members or close community contacts. Through proper monitoring for symptoms, reporting any symptoms immediately, and isolating and testing immediately once symptoms appear, the spread of Ebola to other individuals is limited.

Ebola becomes infectious as the virus progresses, thus a person with recent onset of symptoms of Ebola is not likely to transmit the disease. Further mitigating the risk of spreading an infectious virus like Ebola in the United States is this country’s strong sanitation systems such as flushing toilets and running water.

Considering these factors, leading infectious disease and Ebola experts determined that home-quarantine of returning healthcare workers was not necessary to prevent the spread of Ebola in the United States. Compare Ebola with influenza, a disease that kills thousands of Americans each year. A person with influenza may be

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20 See Upshur, supra note 15.
able to infect others for one day before they develop symptoms and before they know they have the disease. With Ebola, it is extremely unlikely for a person to spread the virus before they know they are infected. Further, Ebola can only be spread through bodily fluids while influenza can be spread through respiratory droplets when someone sneezes or coughs. Influenza is spread considerably easier than Ebola.

**What intervention is reasonable and effective? Is the intervention chosen the least restrictive means necessary to protect the public?** To answer this, we must go back to thinking about how the disease is transmitted and the type of risk an individual may pose to the public. In the rare event that an Ebola healthcare worker develops symptoms of Ebola, they will not be contagious in the initial hours when isolation and testing can be arranged. Because of this, home-quarantine is unnecessary and places an undue burden on individuals. Daily monitoring of temperature and for symptoms of Ebola is sufficient to ensure early detection before transmission occurs.

**Is the quarantine being applied consistently and fairly?** Sadly, in the case of healthcare worker quarantines, protocols were not applied consistently. Two persons contracted Ebola on United States soil, Amber Vinson and Nina Pham, nurses who were infected while providing care to Ebola patient Thomas Eric Duncan in a Dallas hospital. These healthcare workers were not under the same quarantine measures that I had endured.

**If quarantine is deemed necessary, is the individual supported and afforded due process?** I have discussed the discrepancies in individual state quarantine laws and my concern that individuals can be bullied if they are not offered counsel. Aside from due process, the policy to quarantine an individual must also include support such as a comfortable and safe environment to carry out the quarantine, food and basic necessities, and finally, financial compensation to ensure the individual is not at financial risk when the quarantine ends.

**VI. CDC Guidelines Left Room For Politics**

Before I landed in Newark, I had read the United States Centers for Disease Control and Prevention’s “Guidance for Monitoring and Movement of Persons with

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24 See Upshur, supra note 15.
25 See Upshur, supra note 15.
26 See Blinder, supra note 21 and accompanying text (detailing Dallas nurse Ebola cases after treating patient returning from West Africa).
27 See Upshur, supra note 15.
Potential Ebola Virus Exposure” ("CDC Guidelines") at least five times. The shortcomings of the CDC Guidelines were not apparent to me until after my return. As I re-read the CDC Guidelines, the ambiguity and failure to offer a standardized, scientific approach glared back at me. The guidelines mistakenly use inflammatory language when categorizing people as “high risk” or “some risk.” The use of the word “risk” confused the general public and gave politicians and members of the media fuel for their flames. People heard the word risk and inferred that the risk was to the public. In reality, the assessment points to the risk to the healthcare worker who treated Ebola patients.

Second, although the CDC did not recommend a blanket home-quarantine for all returning Ebola healthcare workers, those caring for patients in an Ebola Treatment Unit in West Africa, like me, were placed in the “some risk” category. Recommendations for monitoring asymptomatic workers in this category unfortunately included the following: “the public health authority, based on a specific assessment of the individual’s situation, will determine whether additional restrictions are appropriate.” The lack of further explanation or guidelines allowed state public health agencies and politicians, with no experience or expertise in Ebola, to apply non-evidence-based policies and ad hoc decisions. For example, the state of Maine implemented a protocol involving home-quarantine for all returning healthcare workers, regardless of any individual exposure assessment.

This approach is in contrast to the evidence-based guidelines of the European Centre for Disease Prevention and Control ("ECDC"), which leaves out the word “risk” in describing an “individual exposure assessment” for Ebola healthcare workers. Compared to the United States CDC guidelines, the European model describes the recommended action for individuals in different categories of exposure in a way that is simple, clear, and evidence-based. Severe restrictions are only recommended for healthcare workers with a known exposure to bodily fluids of an Ebola patient.

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29 Id.
30 See id.
31 Id. (emphasis added).
33 See infra note 36 (providing European guidance).
VII. Summary of CDC Interim Guidance for Monitoring and Movement of People Exposed to Ebola Virus

Public health authority will ensure, through orders as necessary, based on a specific assessment of the individual's situation, will determine whether additional restrictions are appropriate, including:

- Controlled movement: exclusion from long-distance and local conveyances (aircraft, ship, train, bus and subway)
- Exclusion from public places (e.g., shopping centers, movie theaters), and congregate gatherings
- Exclusion from workplaces for the duration of the public health order, unless approved by the state or local health department (telework is permitted)

See supra note 28 (containing recommendations for monitoring persons potentially exposed to Ebola).


<table>
<thead>
<tr>
<th>Type of exposure</th>
<th>Proposed option(s) for measures</th>
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<tbody>
<tr>
<td>No direct contact with EVD patients or their bodily fluids (e.g. involved in training local HCWs)</td>
<td>Passive monitoring</td>
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<tr>
<td>Appropriately protected contact with bodily fluids of EVD patients (e.g. laboratory worker), fomites (e.g. bed linen) or during clinical activities</td>
<td>Active monitoring</td>
</tr>
<tr>
<td>Unprotected, inappropriately protected contact or known breach of protection while caring for an EVD patient, handling bodily fluids of a patient, or fomites</td>
<td>Active monitoring, Restriction of engagement in clinical activities, No travel abroad</td>
</tr>
<tr>
<td>Mucosa or parenteral direct contact with bodily fluids of a patient (e.g. pricking a finger with a needle used for a patient or getting bodily fluid projection in the eyes).</td>
<td>Active monitoring, Restriction of engagement in clinical activities, Restriction in social interactions, Restriction of movement</td>
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37 Id.
IX. Stigmatization

A lack of leadership and manipulation of fear led to confusing, inconsistent policies with plenty of wiggle room at the state level. This created a ripple effect, with the American public throwing reason and science out the window. West Africans living in the United States who had not been to their home countries during the Ebola outbreak experienced discrimination.\textsuperscript{38} A Maine public school teacher who visited Dallas during the time Thomas Eric Duncan was treated for Ebola in Dallas was put on leave by the school board for three weeks, simply for traveling to that city.\textsuperscript{39}

Mid-term elections were over in November and the media and politicians moved on to other topics, but healthcare workers returning from West Africa remained the target of stigmatization, discrimination, and isolation.\textsuperscript{40} My experience may seem different than most Ebola healthcare workers who returned after me, but it was not. In the months following my public battle, I received letters and emails from Ebola healthcare workers across the United States who met similar circumstances. They were asked to stay in their homes for twenty-one days.\textsuperscript{41} Their children were taken out of school and they had to fight for their children to return. My partner was asked to stay off the University of Maine at Fort Kent campus where he attended nursing school. He did not sleep well during the week after I returned, concerned for me, frustrated with missing his classes, and unsure of the discrimination he might face when he returned to his University.

We fought against stigma while in Sierra Leone as well. My Sierra Leonean colleagues valiantly cared for patients suffering from Ebola. Some had watched


\textsuperscript{39} Matt Byrne, Maine School Board Puts Teacher on Leave After She Traveled to Dallas, PORTLAND PRESS HERALD, (Oct. 18, 2014) http://www.pressherald.com/2014/10/17/fearing-ebola-strong-elementary-teacher-on-leave-after-traveling-to-dallas/.


\textsuperscript{41} See generally supra note 7 (describing incubation period from infection to onset as twenty-one days).
colleagues, family, and friends die of Ebola, yet they chose to continue providing care instead of retreating to their homes. Many carried the burden of stigmatization because they chose to continue caring for Ebola patients. I listened as a nurse explained that her money was not accepted at the local market because the community was fearful that the money was contaminated since she worked at the Ebola Treatment Unit. Many organizations are still combatting Ebola and the stigmatization that exists in West Africa today. The United States had a chance to respond to Ebola with humanity, reason and strength. We had the opportunity to lead this fight and be in the vanguard of beating Ebola. Instead, we reacted with cowardice and ignorance.

X. Never Too Late

I believe it is never too late to learn from the mistakes made and misinformation spread during this recent Ebola response. Politicians, advocates, experts, and communities must gain knowledge about Ebola, quarantine, and most importantly, we must hold our leaders accountable. I was proud to read the Presidential Commission on Biomedical Ethics regarding the United States Ebola response which stated,

We need to be prepared, for example, to communicate early and often during an Ebola epidemic — drawing upon the best scientific evidence — why not to quarantine asymptomatic individuals. Needlessly restricting the freedom of expert and caring health care workers is both morally wrong and counterproductive; it will do more to lose than to save lives.42

But we cannot stop at the Maine judge's decision regarding my case, the Presidential Commission report, or a legal academic journal article like this one. I hope to see a change in public health quarantine laws. Many states still require Ebola healthcare workers to home-quarantine. We can still provide the necessary leadership on this and other medical issues by questioning the motives of politicians and leaders who ignore the scientific evidence. It is my hope that in the future, individual's civil liberties are fairly balanced with public health concerns and quarantine policies are based on science and evidence instead of fear.
