# Contact Tracing in An Active Pandemic: The Gap Between Practice and Academic Discourse

by

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A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved April 2022 by the
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ARIZONA STATE UNIVERSITY

May 2022

ABSTRACT

Contact tracing was deployed widely during the COVID-19 pandemic to attempt to stop the spread of SARS Co-V-2. This dissertation investigates the research on contact tracing from a scientometric perspective and looks qualitatively at how case investigators and contact tracers conducted public health practice during the pandemic. Through approaching the public health practice of contact tracing from both a broad, top-down angle, and an on the ground experiential approach, this dissertation provides insight into the issues facing contact tracing as a public health tool.

ACKNOWLEDGEMENTS

Thanks to my dissertation committee for their mentorship, support, and patience. This would not have been possible without you all. Thank you to Dr. Megan Jehn for the amazing opportunity to work on the frontlines of public health during a global pandemic and helping make this dissertation what it is through your work as my committee chair. Thank you to Dr. Monica Gaughan for sticking with me through many iterations of this project and helping steer me through its numerous phases. Your skills as a researcher, instructor, and mentor are ones I hope to replicate. Thank you to Dr. Dan Hruschka for always asking the tough but necessary questions, and for teaching me to have the confidence to admit when I do not understand something.

Thank you to Dr. Barry Bozeman for introducing me to the Global Tech Mining and Scientometrics Community, who have been incredibly generous with their advice and have consistently supported the ideas behind this research. Thank you to Dr. Michael Simeone for being very patient with me over multiple projects and multiple years.

Thank you to everyone on the ASU COVID-19 Case Investigation Team. From my co-authors Laura Meyer, Jasmine Truong, Dr. Tim Dennehy, Mick Salik, Julia Jackman, to my colleague Jennifer Jackman, to all the amazing case investigators I had the privilege of working with (including my sister Kelsey White). There's no other team I'd rather build a plane with as we fly it.

Thank you to all my co-faculty at Mayo Clinic Alix School of Medicine for supporting my interest in ethics. Special thanks to Dr. Patty Mayer for always being there to chat and even offering guidance on how to respond to ethics conundrums in an active pandemic.

Thank you to all the faculty and colleagues at SHESC that I have worked with over the years. Without you all I this would not have been possible. Special thanks to Dr. Hjorleifur Jonsson for stoking my interest in ethics in my first year of my PhD and for letting me take your ethics course twice. Additional special thanks to Dr. Amber Wutich for introducing me to the world of anthropological methods and giving me my first "real" research assistantship.

This research was supported by multiple awards including the National Science Foundation Science of Science and Innovation Policy Doctoral Dissertation Research Improvement Grant [Award 1633509], research and writing grants from the School of Human Evolution and Social Change, and travel grants from Arizona State University's Graduate and Professional Student Association. This research is also based upon work supported by the Maricopa County Department of Public Health.

As a student of ASU, I acknowledge that the Tempe campus sits on the ancestral homelands of those American Indian tribes that have inhabited this place for centuries, including the Akimel O'odham (Pima) and Pee Posh (Maricopa) peoples, whose care and keeping of these lands allows us to be here today.

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# PREFACE

This dissertation was written and largely conceived during the COVID-19 pandemic. It is situated in a specific time, April of 2022, and place, Phoenix, Arizona. Given that the research landscape, knowledge of COVID-19 and its effects, and the legal landscape are continuously in flux, at the time of reading elements of this dissertation may be outdated.

While each chapter stands alone, to provide context for the overall research, climate, and contemporaneous state of knowledge during the conception and writing of this dissertation, Chapter 2 will discuss the history of the COVID-19 pandemic up to the completion of this dissertation in April of 2022.

# CHAPTER 1

# INTRODUCTION

In the spring of 2020, public health practice in the United States was changed dramatically by the spread of SARS Co-V2 and its accompanying illness COVID-19, across the globe (Schutat, 2020). In Arizona, in the United States, the first wave of COVID-19 cases hit in the summer of 2020 and by late August 2020 there had been 132,434 cases and 2,869 deaths in Maricopa County alone (CDC, 2020a). After years of defunding and neglect[1], public health professionals were suddenly required to explain core public health concepts to the entire population of the United States quickly and effectively.[2] Phrases like "social distancing" went from being a term of art used only by public health practitioners to a key part of the daily lexicon for many people.

One essential public health tool has become a much-discussed component of combatting COVID-19: case investigations and contact tracing.[3] Public health departments regularly conduct case investigation and contact tracing as a means of notifying persons infected with or exposed to communicable diseases and, often, of their need to isolate or quarantine. Despite being a fundamental element of public health practice, prior to 2020 there did not appear to be a larger public interest in contact tracing. According to Google Trends, the term was hardly ever searched between 2016 and 2019 (See *Figure 1.1*). Since March 2020 a series of exponential spikes in search frequency have occurred.

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[1] *See*, Dixon, et al., 2020; McKillop, et al., 2021.

[2] *See*, Boodman, 2020; de la Garza, 2020; Jacobs & Fink, 2020; Burris & Kapczynski, 2020.

[3] *See*, Bland, 2020; Johns Hopkins Bloomberg School of Public Health, 2020.

Academic research on contact tracing has also exploded. Between 1991 and 2019 there were between 100 to 300 articles per year on contact tracing published and catalogued in SCOPUS per year. In 2020 alone, there were 1332 (See *Figure 3.1*).

Contact tracing is a crucial tool in combatting the spread of COVID-19 (CDC, 2020b). Many states, counties, and even private entities[4] have scrambled to spin up contact tracing teams that can attempt to slow the spread,[5] even as certain states and counties experience thousands of cases a day (Johns Hopkins University & Medicine, n.d.). Estimates from a CDC review of contact tracing efforts from November 2020 to March 2021 indicate that between 39,000 and 56,000 case investigators in the United States interviewed 9.1 million cases and elicited 10.7 million contacts (Rainisch et al., 2022).

What has become visible as COVID-19 has ravaged the United States is that there is a gap between the day-to-day reality of conducting case investigations and contact tracing, and what medical and academic professionals believe is occurring. In a recent Twitter thread, a biostatistics Assistant Professor at University of Florida asked her followers to help her come up with questions to ask "an on-the-ground-team of contact tracers" (Dean, 2020). Questions suggested included:

- "Is it true only 20% of people are answering phone calls from unknown numbers? Are you able to use other methods (Facebook, google searching) to find and contact them? How effective is each method?"

[4] In fact, a March 10th, 2021 search showed most contact tracing jobs on websites like Indeed, Glassdoor, LinkedIn, and Zip Recruiter were for private companies.

[5] *See*, Fortin, 2020; Barry, 2020; Sypher, 2020; Naseer & Strelau, 2021.

- "What are interactions with private companies like? If an investigation leads to a company, do they help? Do they share information about how they test? Develop policies to test regularly?"

While these questions are all valuable and should be asked, it makes clear that those in academia and medicine are unaware of the realities faced by case investigation and contact tracing teams working with extremely limited resources and high volumes of cases. Experiences on the ASU COVID-19 Case Investigation Line indicate that while close to 50% of people complete interviews, only 30% of those give even 1 contact. There are no resources, manpower or otherwise, for any form of follow up if a person is not able to be reached after a limited number of phone attempts. Additionally, there are no resources to contact private companies unless the situation is incredibly dire. Coordination between private companies and public health departments is extremely limited to non-existent.

Additionally, much recent research and publicity on COVID-19 contact tracing focuses on phone apps and digital contact tracing.[6] While these are valuable tools, the reality is apps and devices have struggled to obtain sufficient population saturation to make them widely useful (O'Neill, 2020) and the vast majority of public health departments are still relying on traditional structured interviews to elicit and notify contacts. Health departments around the country have used a variety of programmatic approaches to conduct contact ranging from running investigations themselves in house, to partnering with state universities to meet staffing needs, to contracting out separate companies or entities (Higgins, 2022). Arizona uses a partnering model and Maricopa

[6] *See*, Jahmunah, et al., 2021; Leins, et al., 2020; Chowdhury, et al., 2020.

County partnered with the Arizona State University Student Outbreak Response Team (SORT) for assistance with case investigations and contact tracing.

These partnering models, present in 23 states, may affect the reality of how investigations are conducted. For the ASU COVID-19 Student Outbreak Response Team (ASU SORT), most of the case investigators are volunteers with little or no medical or social work training receiving no pay for their work.

Concerns about contact tracing are also vague and misplaced on the legal side. For example, in its COVID-19 and Privacy Law FAQ, The Network for Public Health Law, a nonprofit that specializes in providing public health legal assistance and technical support, discusses HIPAA and COVID-19 disclosures to close contacts generally, but does not address or explain common legal situations faced by case investigators such as confirming identity via phone and potential HIPAA violations when using proxies to complete interviews (Healy Boufides et al. 2020).

There is a clear gap between what academics are focusing on and what practitioners in the United States actually are encountering in their use of contact tracing to reduce transmission and rates of COVID-19. This dissertation uses a broad sociocultural anthropology approach to address this gap and examine the research context, culture, and practices of a specific group: contact tracers working on COVID-19.

**Research Questions**

In order to interrogate the context and culture of COVID-19 case investigators, this research leverages several different types of data, including natural language data and network analyses of papers on contact tracing, semi structured interviews with on the ground contact tracers, and analysis of legal ethical roadblocks faced by contact tracing team decision-makers.

This dissertation work aims to use these varying forms of data to investigate the gap between academic discourse and actual practice of public health contact tracing during an active pandemic.

This dissertation will answer the following key questions:

1. What are the patterns of research in contact tracing across both scientific academic (SCOPUS) and legal (NexisUni) databases over time and how are those patterns affected by disease outbreaks such as COVID-19?

2. What are the types of barriers to case investigators eliciting contacts during the first year of the COVID-19 pandemic?

3. What are the legal and ethical hurdles that are faced by case investigation teams responding to the COVID-19 pandemic?

To examine the larger research context around contact tracing, this dissertation first looks at the research landscape of articles published on the topic. While much scientific research has mapped fields and their changes over time such as library and information science (Miyata et al., 2020), cancer research (Wu et al., 2018), and even COVID-19[7], this dissertation investigates legal academic articles in a way that has not been previously done: looking at language usage in articles on contact tracing across both scientific and legal academic databases.

Scientometric data on articles on contact tracing from SCOPUS and NexisUni were collected in August of 2021 (Chapter 4). This dissertation analyzed these data to create thematic topics using latent Dirichlet allocation and then mapped the articles based on their topic similarity to investigate the changes in the research patterns over

[7] *See*, Fassin, 2021; Cheng et al., 2020; Ebadi et al., 2020; Coccia, 2021; Zhang et al., 2021.

time. This chapter shows the effect of COVID-19, as well as other disease hot topics, on entire research fields across science and the law.

To uncover the culture and practices of contact tracers working on COVID-19, this dissertation draws from my own experiences on the ASU SORT, as well as interviews conducted with team members. While other researchers during the pandemic have produced qualitative research on contact tracing teams, this research is the first to focus on the barriers to eliciting contacts and the legal and ethical challenged faced by contact tracers.

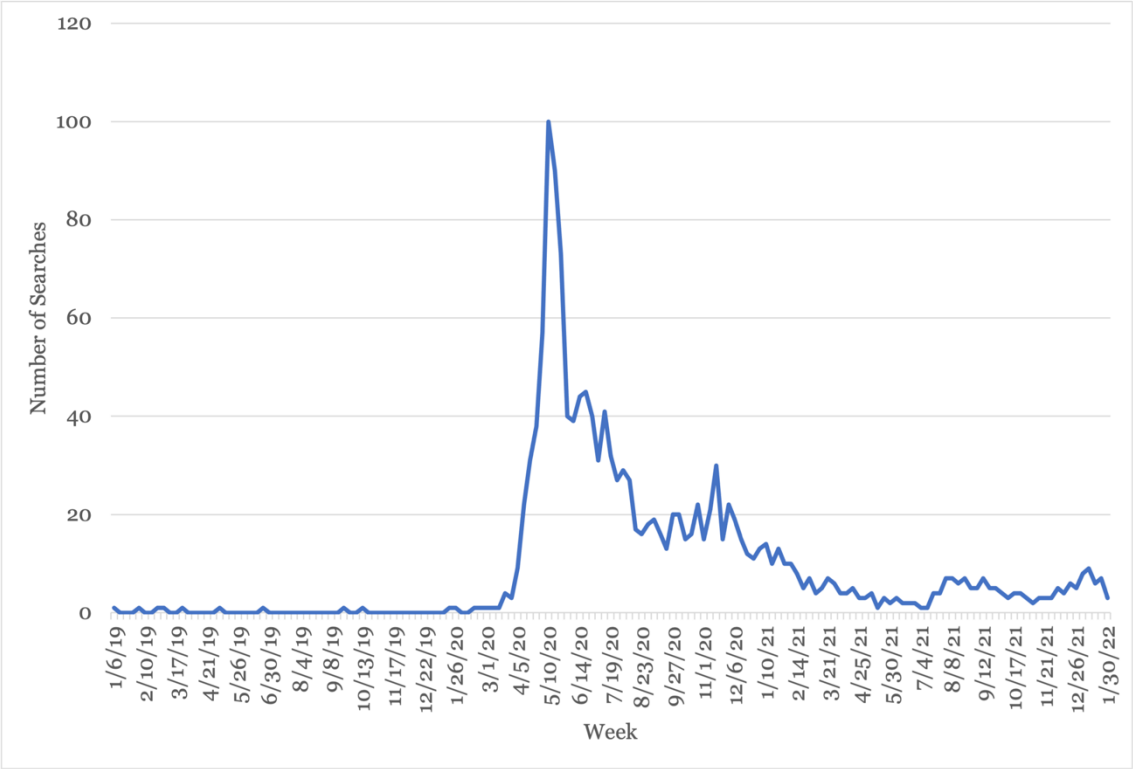
Fourteen semi-structured interviews were conducted with case investigators in late Spring and early Summer of 2021 (Chapter 5). This dissertation used thematic interpretive analysis to induce themes from this data.

I was an active leader on the ASU SORT, and given my legal background and interest in ethics, I was involved in early decisions by the ASU SORT on how to address legal and ethical conflicts as they arose on the case investigation line. The experiences of the decision-making team and the implications of these conflicts are written up in Chapter 6.

This dissertation concludes with a wrap up and a discussion of the implications of this research for public health practice (Chapter 7). The findings in these chapters offer novel contributions to scientometric literature, public health practice research, and legal epidemiology. The hope is that this research as a whole can better guide communication between public health researchers, public health lawyers, and public health practitioners.

## Figures

*Figure 1.1: Google Searches for the term "contact tracing" between 2019 and 2021*

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CHAPTER 2

THE COVID-19 PANDEMIC

## SARS CoV-2, Coronavirus, and COVID-19

COVID-19, also known as the coronavirus disease 2019 is a disease caused by the SARS-CoV-2 virus (CDC, 2021b). It was first discovered in Wuhan, China in December of 2019 and spread rapidly around the world (Gouvea dos Santos, 2020). The World Health Organization (WHO) declared COVID-19 a pandemic on March 11th, 2020 (WHO, 2020b) and by March 13th, 2020 the United States declared a national emergency (Trump, 2020). Over the course of the pandemic, many US states individually declared public health emergencies as well (National Academy for State Health Policy, 2022).

COVID-19 causes a variety of symptoms typical of viral pneumonia, including fever, cough, sore throat, headache, and fatigue, as well as other more specific symptoms including loss of taste and or smell, gastrointestinal issues, and even a condition called COVID-toes.[8] COVID-19 cases can also present with no symptoms, with estimates for the original variant indicating that as much as 25% of cases were asymptomatic (Alene et al., 2021). Symptoms generally appear between 2 and 14 days after exposure and evidence as of April 2022 indicates that the virus is spread in aerosols from infected peoples' mouth or nose as they cough, sneeze, speak, or breathe (CDC, 2021b). There is also the possibility of fomite transmission when a person touches their eyes, nose, or mouth after touching a surface contaminated with virus (WHO, 2021b). Currently, evidence indicates that individuals can become infectious 2 to 3 days before they exhibit symptoms and remain infectious for 7 to 9 days (CDC, 2022d). Some research indicates

[8] COVID toes are painful red or purple lesions on the toes of people with COVID-19 (Rabin, 2020).

that infectiousness can even last up to 20 days after experiencing symptoms or testing positive (Johns Hopkins Medicine, 2022). With the Omicron variant, there is some indication that infectiousness wanes after only 2 to 4 days (CDC, 2022d).

While the isolation guidance for positive individuals has changed several times during the pandemic, CDC guidance in February of 2022 recommends isolation for 5 days and to wear a fitted mask for 10 days (CDC, 2022d). Guidance from the United Kingdom's National Health Service at the same time recommends only exiting full isolation after 5 days if the individual has tested negative for coronavirus two times in a row (NHS, 2022).

COVID-19 can range from mild to extremely critical. Over the course of the pandemic, as of April 2022, WHO estimates that globally there have been over 497 million cases and 6 million deaths (WHO, 2022b). In the same period, approximately over 80 million of those cases and 983,000 of those deaths occurred in the United States (The New York Times, 2022b). Over 1.27 million of those cases and 17,000 deaths occurred in Maricopa County, Arizona where this research was conducted (Arizona Department of Health Services, n.d.; Maricopa County, n.d.).

In addition to the acute effects of COVID-19, some individuals also experience "long COVID," a condition where old and new symptoms may persist for months or even years after initial infection. New symptoms range from neuro psychiatric conditions like depression and anxiety (Kelly, 2022) to heart disease (Jing, et al. 2021). These long COVID problems can potentially occur even after a mild COVID infection that does not lead to hospitalization (van Kessel et al., 2022). New research is consistently turning up additional negative long tail effects of COVID-19 (*See*, Douaud et al., 2022; Barrett et al.,

2022; Bowe et al., 2021) and some have even called it a “mass disabling event” (Roberts et al., 2022).

Different aspects of COVID-19, including transmissibility, severity, and symptoms are very different based on the location, time, and variant of the disease. Between January 2020 and April 2022, there have been 5 SARS-Co-V-2 designated variants of concern: Alpha, Beta, Gamma, Delta, and Omicron. Each of these variants is a mutation of the virus that has significant changes to either its transmissibility, epidemiology, clinical presentation, and or the effectiveness of public health measures including diagnostic tests, vaccines, and therapeutic treatments (WHO, 2022b).

As of April 2022, the COVID-19 virus is still evolving and much remains unclear about COVID-19 and its progression. The infection fatality rate varies widely depending on the age, ethnicity, geographic location, and income level of cases (Ioannidis, 2021), as do the basic reproduction rate ($R_o$) and effective reproduction rate ($R_e$). While initial estimates for SARS-CoV-2’s $R_o$ were between 1.5 and 3.5 (Eisenberg, 2020), further research has shown in the United States it may be has high as 5.9 (Ke et al., 2021). With the potential for new variants with differing transmissibility remaining, it is difficult to conclusively delineate many aspects of COVID-19 at this point.

**United States COVID-19 Public Health Response**

In response to the COVID-19 pandemic, US states and local governments, as well as their populations have responded in varying ways. Governments at all jurisdictional levels, from federal to state to county to city, have employed a suite of public health tools including isolation and quarantine, testing, masking, social distancing, vaccination, and contact tracing to try and slow the spread of SARS-CoV-2 (David J. Sencer CDC Museum, n.d.). The purposes of this section are not to provide an exhaustive overview of

US public health response to COVID-19, but instead offer a few examples of different types of interventions that have been used during the first two years of the pandemic.

*Isolation and Quarantine*

Isolation is the public health procedure whereby individuals who are sick with an illness are physically separated from people who are not sick. Quarantine is the separation or restriction of movement of individuals who have been exposed to an illness to see if they become sick (United States Department of Health and Human Services, n.d.).

Early in the pandemic, Rhode Island imposed (and later rescinded) a blanket quarantine order for New Yorkers traveling to the state and was threatened with a lawsuit by New York governor Andrew Cuomo (Pereira, 2020). Florida also required a 14-day quarantine for travelers flying from New York, New Jersey, or Connecticut in March of 2020 (DeSantis, 2020; WFTS Digital Staff, 2020). Months later in July of 2020, some states, like New Mexico imposed a 14 quarantine for all travelers entering the state (The State of New Mexico, 2020). Two years into the pandemic all contiguous states have lifted any location-based interstate travel restrictions, although some international restrictions remain. Hawaii was the last state with travel restrictions, and it retained a vaccination or negative testing requirement to enter the state until March 26th, 2022 (State of Hawaii Department of Health, n.d.).

In 2021 COVID-19 isolation and quarantine guidance shifted to recommendations about individual decisions when exposed directly to COVID-19. While the initial isolation recommendation for those testing positive for COVID-19 was 10 days, as of February 2022, in the US it is only recommended that individuals isolate for 5 days after receiving a positive test (CDC, 2022d, CDC, 2022g).

*Testing*

Testing refers to using a tool to assess whether an individual has a given illness. Testing can be diagnostic, to confirm illness in those who are symptomatic or exposed, or it can be for screening purposes, to blanketly assess those in a given location, such as a place of employment (CDC, 2021a).

Responses early in the pandemic were hampered by extremely limited testing supply and infrastructure (Mervosh & Fernandez, 2020). Initial testing was primarily polymerase chain reaction (PCR) testing that detected SARS CoV-2 genetic material after collecting a sample using a deep nasal swab. Shortages of nasal swabs, tubes, and testing solutions or viral transport media continued to plague testing into the summer of 2020 (Pfeiffer et al., 2020). By late 2020, testing infrastructure expanded and antigen tests that used saliva became more common.

Despite increase in testing availability, COVID-19 case surges throughout 2021 and into 2022 have overwhelmed testing capacity.[9] By January 2022, despite the existence of rapid at home tests that provide results within 15 minutes, many Americans were struggling to access testing (Santhanam, 2022). On January 19th, 2022, President Biden created a program to allow households to order 4 free rapid tests (The White House, 2022). Other municipalities, like New York City, also attempted to shore up testing capacity by making free rapid tests available at libraries (NYC Health + Hospitals, 2022).

*Masking*

[9] See, Stein, 2020; Berge, 2022.

Masking refers to the placement of material, be it cloth or medical grade textile, over the mouth and nose of an individual to reduce the aerosols that are expelled from their mouth during breathing, talking, sneezing, or coughing (CDC, 2022f). Masks currently have a broad definition that includes both homemade fabric coverings as well as highly regulated and tested medical grade N95 filtration masks.

In the first months of the pandemic there were shortages in high filtration N95 and surgical masks (Khazan, 2020). Even once shortages abated, there was confusion and unclear guidance from agencies like the CDC as to whether masks were appropriate, and the CDC did not recommend face coverings to reduce the spread of COVID-19 until July of 2020 (CDC, 2020c). Mask guidance has also shifted over time in response to the availability of vaccines. In May and June of 2021, some jurisdictions and businesses tied mask policies to vaccination, allowing fully vaccinated individuals to be exempt from mask mandates (Darnell, 2021). Unfortunately, due to spiking case rates, the CDC again recommended masking for all people, including those who were fully vaccinated in late July of 2021 (Lovelace, 2021).

Masks in particular have become an extremely politized issue, both socially and legally (Kahane, 2021, Giles, 2021). By January 2022, only five states had statewide mask mandates (The New York Times, 2022b). Eight states had explicitly banned mask mandates (Vestal, 2021). In late February 2022, the CDC changed its masking guidance to only recommend universal masking in areas where the newly created COVID-19 "community levels" are high (CDC, 2022h). The new community level metric is based on hospital admissions and bed availability, as opposed to previous metrics that used case numbers or test positivity (CDC, 2022h). In response many jurisdictions and organizations removed their universal mask requirements (The New York Times,

2022b). Individual businesses may still have their own policies regarding masking. As of April 2022, universal masking was still required via federal government mandate on airplanes, trains, and in transit hubs (Shepardson, 2022).

Initial guidance around masking focused on the need universal masking to retain effectiveness and reduce the amount of potentially contaminated aerosols present, especially in enclosed spaces (Howard et al., 2021). In the wake of the extremely contagious Omicron variant and relaxed masking, more discussion has arisen around whether "one-way" masking is effective as well (Khazan, 2022).

*Social Distancing*

Social distancing is a public health practice that attempts to reduce disease transmission by reducing close contact between people. It can involve canceling large events like concerts or even suspending schools (Pearce, 2020).

In the first few months of the pandemic, many states and localities enacted orders around social distancing. These ranged from requiring all non-essential businesses to close to reducing the capacity of gyms to suspending elective surgeries (Song et al., 2020; Miller, 2020; Levine, 2020; Hochul et al., 2021). Social distancing measures included measures like suspending indoor and even outdoor restaurant dining (Addison, 2021). In the first few months of the pandemic, 42 states, including Arizona, issued some form of "stay at home" order directing residents to stay at home as much as possible. The US "stay at home" or shelter in place orders were at no point as strict as orders in European cities which strictly limited any trips outside of residences (Kingsley, 2020).

*Vaccines*

Vaccines are a preparation, usually an injection, that generate an immune response in the body against a particular disease that allows the individual some amount of protection from exposure to that disease down the line.

Despite being a novel virus, vaccines for COVID-19 were available to the public in the US by mid-December 2020, just 9 months after an emergency was declared (Guarino et al., 2020). An expedited trial process and unprecedented resources, both monetary and temporal, allowed for the rapid development and release of COVID-19 vaccines (Ball, 2020).

As of April 2022, there are three vaccines approved for use in the United States for individuals aged 18 and up (Pfizer-BioNTech, Moderna, and Johnson & Johnson), with one of those vaccines (Pfizer-BioNTech) approved for those aged 5 and up (CDC, n.d.). As of April 2022, Pfizer and Moderna follow a two-dose regimen with each dose given 21 and 28 days apart respectively (CDC, 2022i). A booster dose follows 6 months after the first dose for both as well (CDC, 2022c). Johnson & Johnson is a single dose with a booster dose 6 months later. There remain questions about whether going forward more boosters will be recommended (Watson, 2022).

Even with the availability of vaccines for COVID-19 in the United States, uptake remains only moderate. Decades of anti-vaccine misinformation have made high vaccine rates elusive (Hotez, 2021). Like masks, vaccine mandates have become incredibly fraught, politically (Wise, 2021), socially (Hagan et al., 2022), and legally. In January 2022, the US Supreme Court issued two opinions – one allowing the federal Centers for Medicare and Medicaid Services (CMS) to require all employees at facilities receiving

federal money to be vaccinated (Biden v. Missouri, 2022), and one striking down the federal Occupational Safety and Health Administration's (OSHA) covered worker vaccine mandate that required all employees subject to OSHA oversight to be vaccinated (NFIB v. OSHA, 2022 )

**Contact tracing**

Contact tracing is a public health technique that allows for the monitoring or slowing of the spread of a contagious illness by identifying and notifying the people who have been infected or exposed (WHO, 2021a). Contact tracing is a prominent public health tool and has been in use since at least the mid 16th century (Cohn & O'Brien, 2020). Technological advances such as the telephone, testing, computers, and even GPS have changed contact tracing over the past century, however the basic components remain the same: find those infected or exposed to an illness and elicit from them who they have been exposed to (or have exposed themselves) to attempt to break the chains of transmission.

Contact tracing involves multiple components. First, cases must be identified via testing and reporting (CDC, 2022e). Then positive cases must be contacted and investigators must determine where they have been and who they have been in close contact with. This component is sometimes referred to as case investigation. Once a list of close contacts has been generated, those individuals are contacted and instructed to quarantine until they are no longer likely to be contagious. The key component is breaking transmission chains by stopping those who may be contagious from spreading COVID-19 to others (CDC, 2022e). For contact tracing to reduce transmission and cases, there also needs to be a robust system for testing to identify positive cases and clear

instructions and opportunity for isolation and quarantine for those who are positive or those who have been exposed (CDC, 2022e).

Starting in March of 2020 contact tracing was put forward as an essential public health tool to combat COVID-19 by the Association of State and Territorial Health Officials (ASTHO) (Fraser et al., 2020), the National Association of County and City Health Officials (NACCHO) (2020), and CDC (2020e). As of April 2022, over 1,300,000 individuals had enrolled in the Johns Hopkins free COVID-19 Contact Tracing Coursera course and the original creator of the course has even launched a second course on how to measure and maximize the impact of contact tracing programs (Gurley, n.d.; Gurley et al., n.d.).

Many in the public were initially optimistic about the utility of digital contact tracing applications and automatic contact tracing using mobile phones in the United States (Greenberg, 2020; Nield, 2020; Pegoraro, 2021). While some states offer exposure notification, it requires users to opt in and low usage make their utility extremely limited (Ladyzhets, 2021). Given this low uptake and concerns about privacy (Fendos, 2021), many US public health departments have opted for manual contact tracing where contact tracers individual call and interview each positive COVID-19 case or exposure (Fortin, 2020).

The successes and failures of contact tracing, both digital and otherwise have been a prominent research topic over the past two years (Ladyzhets, 2021). As will be discussed in Chapter 4, research volume on COVID-19 since 2020 has been enormous, and this spike in research on COVID-19 has extended to contact tracing as well. Early in the pandemic several United States localities published overviews of their contact tracing programs including San Francisco, California (Reid et al., 2021), Anne Arundel County

Maryland (Kalyanaraman et al., 2021), and New Haven, Connecticut (Shelby et al., 2021). These program overviews are important to capture how public health practice is actually conducted during the pandemic. These programs will be discussed more in depth in Chapter 5.

**ASU COVID-19 Student Outbreak Response Team**

The first case of COVID-19 was confirmed in Arizona on January 28th, 2020 (KTAR, 2020). By late June 2020 Arizona was regularly seeing over 3,000 cases a day (Neuman, 2020). Arizona experienced even higher peaks in cases in January of 2021 with an average of over 10,000 cases and day and again in January of 2022 at over 20,000 cases a day (The New York Times, n.d.). At various points between May 2020 and April 2022, Arizona has been a global hotspot for COVID-19 cases.[10]

Arizona State University's Student Outbreak Response Team (ASU SORT) was created and launched in 2017 in order to provide the opportunity for students to learn and practice field epidemiology in partnership with state and local public health agencies, including Maricopa County Department of Public Health (MCDPH).[11] SORT gives students hands on training to respond to outbreaks using epidemiological research, modeling, and public health techniques. Students at ASU could join the team by enrolling in an applied epidemiology internship course through the School of Human Evolution and Social Change (SHESC).

Due to the preexisting relationship between MCDPH and the county's pared down staffing model, MCDPH and ASU SORT entered a partnership to expand the ASU

[10] See, Andone, 2020; Jaweed, 2021; Caldwell & Lovett, 2021; Ho, 2021; Tang, 2021.

[11] For a more detailed description of the ASU SORT design and implementation, please see Ledesma, et al., 2022.

SORT and pivot it to a large, rapid, COVID-19 response team. ASU SORT went from a small in-person student team to an over 200-person remote workforce comprised of students receiving course credit, students doing paid work, both full and part time paid staff, and faculty, student, and community volunteers. The team's leadership included members from across disciplines, including epidemiology, social work, anthropology, law, and education.

The existing ASU SORT programmatic infrastructure, as well as the access to university student volunteers and messaging, allowed the team to scale up rapidly and begin handling hundreds of case investigation phone calls within a few short weeks. The case investigation data infrastructure is complex and included multiple steps and checkpoints for data quality and assurance. The programmatic structure of the ASU SORT can be seen in *Figure 2.1*, which was originally produced by Ledesma et al. for their article in Public Health reports. Despite this complex data infrastructure, in its first year of operation, between June 29th, 2020 and July 1, 2021 ASU SORT completed 24,507 case interviews and closed 39,831 cases (See *Figure 5.1*).

ASU SORT investigators call individuals who have tested positive for COVID-19 in Maricopa County on the phone and ask them to complete a 10-to-15-minute survey that includes their demographic information, test date, medical history, symptoms, employment status and history, travel history, vaccination status, and close contacts. For the purposes of COVID-19 contact elicitation, ASU SORT used the CDC criteria of any person with whom the case has been within 6 feet of for more than 15 minutes in the 2 days preceding any COVID-19 symptoms or a positive test. This data is entered into an online Qualtrics survey and is immediately accessible to Maricopa County. Any close contacts are sent to a separate team who will contact them to notify them of exposure.

ASU SORT Case investigators work remotely in two or three hour shifts from 9:00am to 8:00pm Arizona time. Case investigators are overseen by one or two paid shift supervisors who provide updates, technical and emotional support, and monitor the back-end data for cases. Shifts are generally capped at no more than 15 case investigators on a shift to ensure quality control for back-end data monitoring. Supervisors review each interview for missing data and log each closed case[12] in a list for MCDPH. Supervisors also log cases that are sent back to MCDPH for other reasons that include wrong phone numbers, false positives, and cases who speak a language other than English or Spanish.

Case investigators work on a volunteer, course credit, or paid basis. Those with ties to Maricopa County located anywhere in the world may volunteer to conduct case investigations remotely. Students at Arizona State University may enroll in the practicum course and complete case investigation hours as part of their completion of the course. ASU SORT has also hired case investigators from both the student pool and the broader community to complete case investigations as well.

ASU SORT operated continuously from June 2020 to present (April 2022). Over the 22 months of conducting case investigations, ASU SORT has closed 82,162 cases, completed 36,039 interviews, and elicited 31,478 contacts.

**COVID-19 and the Future**

As the COVID-19 pandemic is ongoing, jurisdictions are continuously responding by updating their policies in response to new data around case rates, transmission, and treatment. Even in the final weeks of writing this dissertation many states and localities

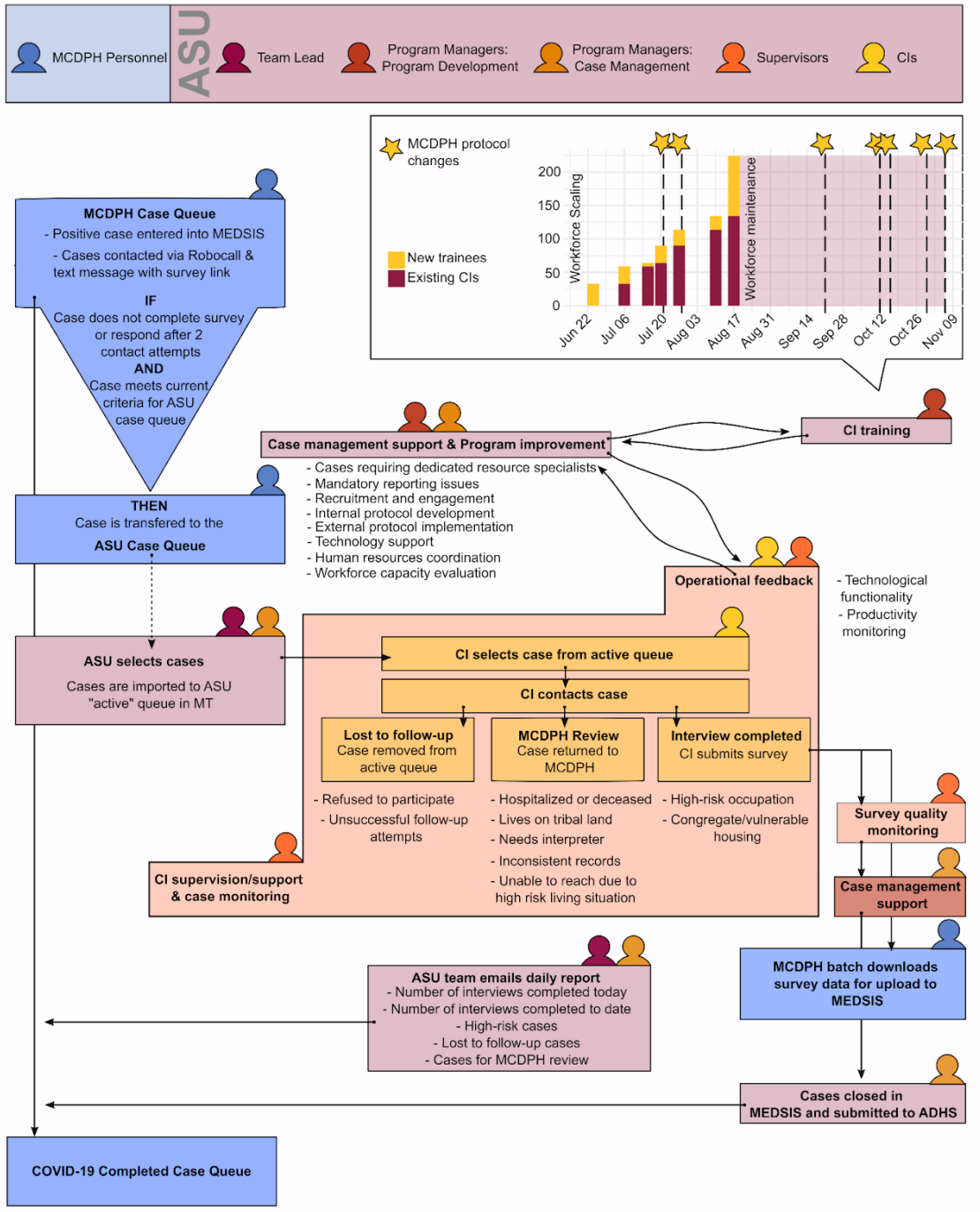
[12] Cases are closed when the interview is completed, or the case is unable to be reached after two unsuccessful attempts on two different days.

drastically altered guidance on key issues like masks and vaccines. New research on the origins, transmission, and long-term effects of COVID-19 is published almost daily. All the information provided in this chapter was current, as of April 2022.

This dissertation seeks to investigate three key areas around contact tracing and COVID-19 and contribute in its own way to the further understanding of a globe-altering phenomenon. It will likely be years before it is clear all the various ways in which COVID-19 has changed the United States and the globe medically, financially, politically, and socially. This dissertation is limited by its positioning temporally (April 2022) and spatially (The United States, Arizona).

## Figures

*Figure 2.1 Programmatic structure of the Arizona State University Student Outbreak Response Team (SORT) (from Ledesma et al., 2021)*



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CHAPTER 3

LITERATURE REVIEW

## Anthropology and Public Health

Anthropology, particularly medical anthropology has been crucial to the expansion of public and global health over the past 50 years.[13] Anthropologists working alongside public and global health practitioners have assisted in improving the lives of many worldwide. Prominent anthropologist cum public health practitioners like Paul Farmer and Arthur Kleinman have brought awareness not only to global public health but the role of anthropology in aiding culturally embedded health interventions.

Anthropology has not always been as welcome in public health spheres as it currently is. Arthur Kleinman reflected that in his early days as a medical anthropologist that anthropology was viewed "as the handmaiden of biomedicine and public health" (2009 at vi). In the middle of the 20th century anthropologists had to argue for their inclusion in the realm of public health. Prominent Anthropologist George Murdock argued in the American Journal of Public Health that "one of the greatest potential contributions of anthropology is to make those who are professionally concerned with health problems aware of the broad sweep of culture history and of their position in it" (1952)[14].

[13] It can be tricky to distinguish between anthropology and public health and anthropology and medicine. This is partially because there frequently is confusion about the distinction between public health and medicine themselves. The American Public Health Association (APHA) explains public health as dealing with populations, as opposed to individuals (APHA, n.d). Public health also focuses on prevention of disease for a population, while medicine deals with prevention, diagnosis, and treatment of individuals (Fineberg, 2011).

[14] As a note, Murdock's 1952 article contains extremely stigmatizing language and racial slurs that even at the time, ignited a response in a second journal, American Anthropologist. Notably, Murdock himself responded and insisted "seemingly I was mistaken in assuming a sense of humor in a lay audience of medical men" (Barkhuus & Murdock, 1952).

Moving into the 21st Century, the relationship between anthropology and public health is now more established. Even at the institution where this dissertation is being written, Arizona State University's School of Human Evolution and Social Change, anthropology and global health are housed in the same department and share faculty. Anthropology, especially medical anthropology, is now viewed as a key tool in global health research and praxis. Some argue that the relationship between anthropology and public health is inimical, with Hahn and Inhorn even going as far as to say "public health needs anthropology to be maximally effective" (2009 at 5).

Anthropology assists both practice and research for many types of public health intervention, and it has been especially useful to public health practitioners globally during disease outbreaks. Anthropological approaches encourage contemplation of the social and economic aspects of epidemics and allow for improved interventions (Farmer, 2010).

For example, Paul Farmer looked at the relationship between the social forces and institutions that harm people, or structural violence, and multi-drug resistant tuberculosis in Haiti. By focusing on individual experiences, Farmer was able to tease out how one low-income man's experience of the Haitian medical and tuberculosis treatment system, mediated by poverty, political climate, and geography led to him suffering from multi-drug resistant tuberculosis for years before succumbing to the disease. Anthropological qualitative approaches allow researchers to see beyond the biological course of the disease and the medical non-compliance to how other structures inhibit treatment and progress (Farmer, 2010).

Anthropology can also be used to tailor interventions, not just explain existing public health systems. Recently, during the 2014 to 2015 West African Ebola outbreaks

anthropologists and their research were essential to public health response (Abramowitz, 2017). Anthropologists advocated for maintaining respect for West African communities and traditional beliefs. This included even arguing to maintain local practices commemorating the dead as opposed to the recommended medical guidance for cremation. Despite the immediate risk with a contagious disease that could be transmitted postmortem, Anthropologists argues that the alienation of these communities through the disregard of their beliefs would be more harmful (Frankfurter, 2014). With these Ebola outbreaks, anthropological knowledge of local communities was leveraged to improve public health interventions

The above research projects are just two examples of the numerous ways anthropology has been used to assist in public health interventions around the world. The incorporation of cultural context to public health is essential.

**Anthropology and COVID-19**

In a recent issue of American Anthropologist, the flagship Anthropological journal in the United States, 17 anthropologists from 16 different countries on six continents were asked if there were aspects of the pandemic that anthropology helped illuminate. The responses show that anthropological training and practice offers a unique lens on an emerging public health phenomena. Rosita Henry, in Australia noted:

> "An anthropological lens helps me to critically observe and understand the different ways that states across the world and their citizens have responded to the pandemic. Anthropology allows me to see beyond the virus, as something affecting the individual body, to the pandemic, as something affecting the social body and as an effect of the body politic. Anthropology leads me to see the virus

not only as a problem for medical science but also a problem for the humanities and social sciences" (Dominguez et al., 2021).

Anthropological approaches offer a broader conception of public health problems like COVID-19 beyond the technical medical details and epidemiological numbers. Janice Graham, in Nova Scotia, Canada offers further discussion of the role of anthropology and anthropologists in responding to the COVID-19 pandemic:

> "Anthropology provides the conceptual tools and real-world evidence to engage locally with the complex biological, historical, social, and economic elements of a global pandemic. Structural conditions and community cultural values differentiate between health systems that protect or neglect. Worldwide, anthropologists are being deployed to engage with communities in the broadest sense across expert and civil societies in correcting the pervasive structural, biological, and economic inequities: such has always been the work of anthropologists. SARS-CoV-2 is not an equal opportunity disease. Emergent anthropological approaches are best suited to recognize these holes in existing structures and through applying meaningful local ecological knowledges, to build post-pandemic paths forward" (Dominguez et al., 2021).

Like many disciplines, Anthropologists have pivoted their research to focus on COVID-19 and its numerous, multifactorial challenges.

Hahn and Schoch-Spana discuss four principles of anthropology that underpin public health and explain how each is particularly relevant in the context of the COVID-19 pandemic (2021). First, anthropology offers a lens as to what counts as sickness, disease, or injury as historically and socially situated, as well as value laden. In the context of COVID-19 they point to the controversy over calling COVID-19 the "Wuhan

Virus," "foreign virus," and "kung flu" all as underpinning conceptions of the disease, reifying political fault lines, and affecting behavior.

Secondly, anthropology offers key insights into how societies are organized and affect epidemics as social phenomena. In the United States, anthropology can help show the interplay between race, income, and COVID-19. Systemic racism and income inequality have led to Black and Hispanic populations employed in jobs with higher risk of COVID-19 and thus higher COVID-19 case rates and deaths.

Third, anthropology can offer recognition of health conditions as a driving factor of societal change itself. While the long-term structural changes from COVID-19 are not yet clear, in the United States shifts around remote work are already visible and have already begun to affect society as a whole.

Fourth, since public health practice is almost always a cross cultural exercise, even in the United States, anthropology can help describe and navigate social and cultural settings where public health response occurs. Hahn and Schoch-Spana focus on masks as a cultural signifier and discuss how narratives, attitudes, identity, and religion around mask wearing can all affect public health compliance.

Anthropologists have also tackled specific empirical research around COVID-19 response. Rocha looked at the success of vaccination in Bhutan, a country which achieved 93% adult vaccination rates in just two weeks (2021). Berlivet and Lowy looked at the interplay between the epistemological shift in online discourse towards a democratization of science and the discourse around hydroxychloroquine (2020). Ethnographies of migrant construction workers and their experiences of public health quarantine measures were used to discuss spatialization of power relations and political functions of public health (Iskander, 2020). Oyarzun uses their role as a public health

practitioner to observe the relationship between public health, military, and capitalism in the context of the long tail history of slavery (2020).

Anthropological assessments of public health interventions are important for capturing the structural, cultural, and epistemological contexts of public health response to improve future responses. Singer and Rylko-Bauer argue that in the wake of COVID-19 "a priority of anthropology…should not be a rapid return to the world as we knew it, but rather to one in which diminishing the impact of the next pandemic involves addressing social inequalities within society and within healthcare" (2021 at 21).

**Applied Anthropology and the ASU Student Outbreak Response Team**

Fundamentally, this dissertation is the study of the culture of one specific COVID-19 public health intervention: contact tracing. This research focuses on the Arizona State University Student Outbreak Response Team as a field site, but pulls in the larger scientific and legal research on contact tracing to serve as a structural and cultural background. This dissertation uses an overarching applied anthropological approach to investigate the larger research structure and culture around COVID-19 contact tracing, the lived experiences of COVID-19 case investigators, and the practical ethical and legal challenges of conducting case investigations during the COVID-19 pandemic. A broader anthropological evaluation research approach informs each of these subsections (Trotter et al, 2015). The three main papers that make up this dissertation each use a different approach to interrogate a particular aspect of public health contact tracing practice.

**Scientometrics**

Scientometrics is the study of scientific communication through quantitative indicators (Leydesdorff, 2001). This science of science looks at anything from academic journal articles to patents as research texts and can leverage a variety of techniques to

tease out the relationships between scientific disciplines, within research fields, amongst countries, or even the researchers themselves. Scientometrics uses numerous quantitative techniques to explore scientific research, but two major approaches in the field are bibliometrics and text mining.

*Text Mining*

In order to look at the scientific and legal academic context for contact tracing, this dissertation looks at the body of research on contact tracing and the linguistic patterns of contact tracing across scientific and legal disciplines. This research will specifically use topic modeling, a form of text mining that uses words or phrases to illustrate potential underlying structures or relationships in the corpus of documents (Yau et al., 2014).

Fundamentally, text mining identifies and explores patterns from the unstructured text in a document collection (Feldman & Sanger, 2007).[15] Though the statistical techniques and models for applying topic modeling have changed over time, certain key assumptions underlie them all. Primarily, topic modeling ignores the order of documents in a corpus and the order of words in a document (the "bag of words" assumption). While this "bag of words" assumption may make anthropologists and linguists who prize sematic structure nervous, context is not necessary, and in fact is problematic when converting a document and document corpus into vectors for processing.

[15] According to Feldman and Sanger in their seminal textbook on text mining: "the core functionality of a text mining system resides in the analysis of concept co-occurrence patterns across documents in a collection. Indeed, text mining systems rely on algorithmic and heuristic approaches to consider distributions, frequent sets, and various associations of concepts at an inter-document level in an effort to enable a user to discover the nature and relationships of concepts as reflected in the collection as a whole."

The key advantage of topic modeling is it allows a researcher to glean key information from enormous bodies of work. For example, if I were to attempt to read and code all 4887 article abstracts on contact tracing for just the presence or absence of a single code, it would be time prohibitive. However, through text mining techniques like topic modeling large document sets can be broken down into manageable pieces. Most importantly, topic modeling is a tool that requires extensive pre-processing and structure on the front end, and extensive interpretation on the back end. Topic modeling is not a plug-and-play hypothesis validator. The output is not designed to be a stand-alone result. Outputs require careful interpretation. All outputs gleaned from topic models applied to this research are to be complimented on both pre-processing and interpretation with theory and grounded ethnographic data.

Topic model application essentially involves five key components: document collection or corpus, technique, unit of analysis, post-processing, and visualization (Tempelton, 2011). While document collection will be addressed later, this section will look at the potential issues arising in pre-processing, selection of technique, unit of analysis, post-processing and visualization.

Topic modeling evolved from information retrieval techniques on *tf-idf* or term-frequency-inverse document frequency, a basic statistic that looks at the number of occurrences of a word in a document compared to the inverse document frequency count, or frequency of the same word in the entire corpus (Blei et al., 2003). From this simple ratio, latent semantic indexing or LSI emerged to offer better dynamic clustering and reduce the sheer number of divisions in the text. Probabilistic LSI, or pLSI was seen as big improvement on LSI, since it modeled co-occurrences using conditionally independent multinomial distributions, as opposed to the singular value decomposition

of LSI. However even with this improvement, one of the shortcomings of pLSI is that due to the equational structure, as the number of documents in the corpus grows, so do the number of parameters in the model, and so overfitting of the data occurs and becomes problematic with a large corpus (Blei et al., 2003).

*Latent Dirichlet Allocation (LDA)*

The current most popular model in topic modeling is a technique called latent Dirichlet allocation, or LDA (Yau et al. 2014). First proposed in 2003 by Blei, Ng, and Jordan, LDA creates a set of topics that contain all words in the corpus. This technique uses a Bayesian probabilistic model to represent "random mixtures over latent topics, where each topic is characterized by a distribution over words" (Blei et al. 2003). Since LDA assumes that all words in the corpus are included in at least one topic, the number of topics must be specified at the outset. This can be problematic for researchers who have to decide from the beginning how many topics they think can accurately capture the entire body of work. Additionally, no information is gleaned regarding the relationship between topics. Despite these shortcomings, LDA remains heavily used, especially by those in the humanities and those more interested in using the tool to create an output, as opposed to perfecting the tool. The primary software for topic modeling, Machine Learning for Language Toolkit, or MALLET uses the LDA process, although it currently has options for two other techniques.

Topic modeling can generally be applied to any text containing words, be it a legal brief, a recent legislative bill or even a power point presentation. The unit of analysis refers to the "document," while the corpus refers to the collection of documents. The unit of analysis can be a sentence, a paragraph, a research paper or even a whole novel. For the purposes of this research, the unit of analysis will be the individual paper.

Beyond the unit of analysis for the document, documents themselves can be broken down into words or multi-word phrases. Documents can be tokenized (divided into sentences, or some other structure) and lemmatized (grouping together different inflected forms of a given word stem) to mitigate problems of context (Feldman & Sanger 2007). All of these elements are crucial components of data pre-processing that affect the equation and output. While some research indicates that multi-word phrasing pre-processing does not assist in topic output (and in fact may even be harmful to results (Yau et al. 2014), in the particular topic areas for this research an argument can be made that multi-work phrasing is necessary.

Once a given topic modeling technique has generated topics, it is up to the researcher to interpret the data. Topics generated in the output are simply a list of words, and typically the researcher assigns a label to each topic that represents its theme. Beyond labeling these outputs, in order to analyze and interpret the output, some sort of additional visualization is necessary (Chaney & Blei, 2012). Software packages and scripts created by computer scientists integral in topic modeling allow for exploration of topics for better understanding by the researcher (Chaney & Blei, 2012, Murdoch & Allen, 2015).

However, for use in publication or presentation further visual and conceptual refinement is required. Most articles and presentations that use topic modeling apply additional techniques to the resulting topic data. These include things like a simple visualization of words in a given topic or even the use of words in a topic over time. However, more useful are the techniques that involve further processing, such as network graphs, which require the creation of a correlation matrix of topics against topics, then the input of those correlations into an addition visualization software

package such as Gephi (an open source visualization software) or ORA (a dynamic met-network assessment tool from Center for Computational Analysis of Social and Organizational Systems (CASOS) at Carnegie Mellon) to illustrate the network.

Chapter 4 will discuss in detail how scientometric approaches, including both bibliometrics and topic modeling have already been applied to study the phenomenon of COVID-19 research. By way of a preview, current research has already looked at various aspects of article volume (Zhang et al., 2020; Coccia, 2021; Teixeira da Silva et al, 2020; Bejamens et al, 2020; Aviv-Reuven & Rosenfeld, 2020; Ho & Liu, 2020; Lucas-Dominguez et al, 2021) as well as topic models (Cheng et al., 2020; Ebadi et al., 2020; Zhang et al., 2021).

By looking at the text and themes of articles on contact tracing across both SCOPUS and NexisUni in the context of the COVID-19 pandemic this research will explore the scientific and legal research contexts in which current contact tracing operates. While not traditionally an aspect of anthropological research, this scientometric approach expands the understanding of how research on a public health technique operates.

**Qualitative Research and Anthropology of Public Health Practitioners**

While anthropology can be helpful in assessing the structural, cultural, and other factors that affect public health interventions, anthropology can also be turned onto public health practice and practitioners themselves.

The history of anthropologists helping public health in process improvement goes back decades. In 1981 an article was published in the journal Practicing Anthropology on one anthropologist's work as a consultant for the regionalization of public health departments in Kentucky (Mize, 1981). Mize describes using applied anthropology to not

only research the process of combining hundreds of small health departments into larger regional ones, but also intervening in the form of facilitating communication between the state Bureau of Health Services and local actors.

Public health already has its own robust history of qualitative self-evaluation. The RE-AIM Framework, developed by Glasgow, Vogt, and Boles was an early evaluation model which pushed back on the medical clinical trial evaluation emphasis present in public health evaluation (1999). RE-AIM is a tool that looks at the reach and representativeness of an intervention's participants and settings in the real world, as opposed to a "controlled" environment. RE-AIM stands for Reach, Efficacy, Adoption, Implementation, and Maintenance and can be applied to various types of public health interventions to qualitatively and holistically assess.

RE-AIM has already been used to assess several different COVID-19 public health interventions, including contact tracing. The UCSF Benioff Homelessness and Housing Initiative (BHHI), the San Francisco Department of Public Health (SFDPH), and the San Francisco Department of Homelessness and Supportive Housing (SFHSH) used the RE-AIM framework to evaluate their rapid antigen testing program in congregate living shelters (Aranda-Diaz et al., 2022). North Health, a Melbourne Australia public health provider used RE-AIM to assess their telephone-based community monitoring service (Clarke et al., 2021).

Notably, the New Haven Health Department and Yale University joint COVID-19 response team used RE-AIM to evaluate their contact tracing program and look qualitatively at barriers faced by their volunteers during the first three months of the COVID-19 pandemic (Shelby et al., 2021).

While this research does not explicitly use the RE-AIM framework, it builds off of corollary research from ASU SORT that does use RE-AIM and offers a qualitative assessment of case investigator experiences.

**Legal Epidemiology**

Legal epidemiology is a developing transdisciplinary field that explores how laws affect disease and injury in a population (Burris et al, 2020). Legal epidemiology views law and policies as exposures themselves and investigates how particular laws or policies affect community health and outcomes (Goldberg, 2020). During the COVID-19 pandemic, the need for research that assesses the effectiveness, or even the effects of public health laws and policies on disease spread is essential (Burris et al, 2021).

Integrating law and science requires the collaboration of public health researchers, lawyers, and institutions on theories, methods, and practical tools (Burris et al., 2016). Legal epidemiological research can be used to look at everything from insurance eligibility laws on mortality and the impact of zoning regulations on community violence (Benjamin, 2020). In their specialty issue focusing on legal epidemiology, the Journal of Public Health Management and Practice covered topics ranging from tobacco preemption control laws (Kang et al., 2020) to sodium reduction laws (Sloan et al., 2020) to pregnancy alcohol use policies on birth weights (Roberts et al., 2020).

Legal epidemiology is a tricky space – it requires not only legal expertise but also epidemiologic expertise (Burris et al. 2020). Even further, due to the complicated interactions between laws, politics, and social trends, it is incredibly difficult to show how a change in law leads to a particular health outcome. In a 2017 article, Ramanathan et al. discussed their recent 50 state survey on Medicaid prior-authorization

requirements for ADHD medication as a potential predictor of behavioral therapy treatment for young children with ADHD (Hulkower et al., 2017), however they acknowledge that additional qualitative research is needed to assess actual behavior in the researched jurisdictions.

Using legal epidemiology and its focus on how law affects the spread of disease as a starting point, Chapter 6 of this dissertation looks at how the ASU COVID-19 Case Investigation Unit navigated federal, state, and local statutes and regulations, as well executive orders in conducting a key public health disease intervention: case investigation. I am uniquely positioned to apply the transdisciplinary lens needed for legal epidemiology because of my background as an attorney, work as a public health practitioner, and research as an anthropologist. The combination of legal overview, on the ground knowledge of public health process, and anthropologically grounded observations allowed me to integrate approaches, methods, and tools, as well as draw linkages between the laws and policies and the decision-making of the ASU COVID-19 Case Investigation Unit.

The combination of scientometrics, qualitative program assessment, and legal epidemiology allow contact tracing and case investigation to be seen from a variety of methodological lenses. These different approaches show the complex research, cultural, and structural environment in which actual public health practice operates during a pandemic.

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# CHAPTER 4

# TOPIC MODELING ACROSS SCOPUS AND NEXISUNI DATABASES: THE EVOLUTION IN RESEARCH ON CONTACT TRACING ACROSS SCIENTIFIC AND LEGAL DIMENSIONS OVER TIME*

*Note: This chapter is in preparation for submission to *Scientometrics*.

**Abstract** (150 – 250 words): This research identifies topics in literature on contact tracing using latent Dirichlet allocation (LDA) and visualizes the impact of COVID-19 on the structure of the field through transitions of topics across the decades from 1946 to 2020. The abstracts from 4885 research articles on contact tracing from both SCOPUS and NexisUni databases were analyzed using LDA. The data were divided into six subsets based on time periods: 1946 to 1979, 1980 to 1989, 1990 to 1999, 2000 to 2009, 2010 to 2019, and 2020. Seven topics in each period and 25 topics across the entire corpus were labeled and plotted on a two-dimensional map using ORA network analysis software. This research shows the prevalence of contagious diseases such as tuberculosis, HIV/AIDS, COVID-19 as topics across the corpus and in each time slice, as well as the clear topic clustering of legal academic articles from the NexisUni database around specific topics like law and confidentiality.

**Keywords:** Latent Dirichlet allocation (LDA) | Topic modeling | contact tracing | law and policy

## Introduction

In 2019, the COVID-19 pandemic forever changed not only the practice of public health, but the global research landscape. In 2020 4% of global research output focused on COVID-19 (Else, 2020). In the span of two years, in the SCOPUS database alone over 300,000 articles have been published with a title, topic, or keyword related to COVID-19. This research volume is indicative of the large amounts of public attention, research dollars, and academic output across medicine, infectious diseases, and public health that COVID-19 has driven.

This explosion of COVID-19 infectious disease and public health research coincided with more research and information being made available to the public (Mogensen, 2021). Scientists are frequently appearing in the media and academic publishers like Elsevier, Springer Nature, and SAGE are lifting their paywalls for COVID content (Elsevier, 2020; Pring, 2020; SAGE, 2020). Despite both a boom in research and its availability, individual resistance to public health interventions from masking to vaccination and even contact tracing have been rampant in the United States.[16] This backlash to scientific research has brought to the forefront the importance of scientific communication and science-based policy. How scientific research reaches the public and how it is presented has become a minefield in the past two years. Scientists have pointed fingers at poor journalistic standards, sensationalist media, exaggerated university press releases, oligarchical paywalls that prevent non-subscribers from accessing peer-reviewed journal content without paying, and on the opposite end, widely available pre-

[16] *See*, Vestal 2021; Abbott, 2021; Stone 2020.

prints.[17] Fears about poorly executed or even fabricated research being used to direct not only public hysteria, but also actual policy decisions are no longer theoretical.[18]

As the past two years have highlighted, research does not operate in a vacuum. The utility of scientific studies is intertwined with the legal environment. Public health interventions specifically require legal support to be effective. Vaccine mandates,[19] mask mandates,[20] [21] test reporting infrastructure,[22] contact tracing,[23] and even treatment authorization[24] all can be helped or hindered by laws at the federal, state, or local level.

Scientometric research that illuminates trends in research is crucially important. However, most research on linguistic and structural patterns in scientific research leaves

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[17] *See*, Roeh & Feldman, 1984; Riesch & Spiegelhalter, 2010; Sumner et al., 2014; Martin & Kasper, 2000; Resnick & Belluz, 2019; Brierly, 2021.

[18] *See*, Jehn, 2021; Gostin et al., 2020; Sullivan, 2021; Fazio et al., 2021.

[19] In 2022, the United States Supreme Court upheld a federal requirement that employees at medical facilities covered by the Centers for Medicare and Medicaid Services (CMS) be vaccinated for COVID-19, however it struck simultaneously struck down a federal mandate requiring all businesses subject to the Occupational Health and Safety Administration (OSHA) also be allowed to require COVID-19 vaccination (Biden v. Missouri, 2022; NFIB v. OSHA, 2022).

[20] In Arizona, a ban on mask mandates in public schools was overturned as unconstitutional by a lower court judge (Superior Court of Arizona, 2021; Giles, 2021) and ultimately upheld by the state supreme court (Arizona Supreme Court, 2021; Christie, 2021); CDC, 2021.

[21] In January of 2021, the US Centers for Disease Control and Prevention issued a federal order requiring the wearing of masks when traveling on a federal conveyance, such as an airplane (Centers for Disease Control, 2021).

[22] Many state public health departments and governors issues executive orders early in the pandemic designating COVID-19 and SARS CoV-2 a mandatorily reportable disease and required all labs in the state to report all tests and results for COVID-19 to the state health department (Rivkees, 2020; Coleman-Mitchell, 2020; Ducey, 2021). This measure was essential to enable tracking and ultimately contact tracing for COVID-19.

[23] The Congressional Research Service published a 43 page report in September of 2020 providing an overview of federal, selected state, and international data protection laws that had the potential to help or hinder digital contact tracing (Gaffney et al. 2020).

[24] As of March 2022, 26 states have introduced bills related to the treatment of COVID-19 using the controversial anti-parasitic ivermectin (Federation of State Medical Boards, n.d.; Rodriguez, 2022).

out a crucial component: legal academic articles. Legal scholars operate in a publication domain parallel to, but distinct from, scientific academic scholars. Their articles go through a similar (but student driven) peer-review process, and are published in journals accessible through different databases (despite being owned by science data-giants like Thompson Reuters and RELX, formerly Elsevier). Legal scholars also extensively pull evidence from across scientific fields, potentially acting as an information bridge between scientists and policy makers. How scientific authors frame their discussions compared to how legal authors frame their discussion is a key component in the chain of communication between scientific research and policy.

This research assesses articles on contact tracing, a key public health topic, from SCOPUS and NexisUni using topic models. This research has two objectives: one, look at a specific research area of public health, contact tracing, and illustrate how it has changed over time, especially in response to emerging diseases and specifically the COVID-19 pandemic. Second, this research will illustrate the position of legal academic research in a specific space and use novel techniques for incorporating a new database into existing scientometric mapping.

### *Scientometrics and COVID-19*

The volume of COVID-19 research is so significant, researchers are already publishing on its effects on the overall research landscape and even calling it "a disruptive element that no other theme in other sciences has ever achieved" (Fassin, 2021 at 5316). Existing scientometric studies on COVID-19 research have looked at the spike in publications on COVID-19 (Teixeira da Silva et al., 2020), international publication rates (Benjamens et al. 2020; Aviv-Reuven & Rosenfeld, 2020; Ho & Liu, 2020; Lucas-Dominguez et al., 2021), bibliometrics and international collaboration

(Belli et al., 2020; Cai et al., 2020; Abrama & D'Angelo, 2021; Sachini et al ., 2021), co-word analysis (Pourhatami et al., 2021), the use of acronyms in COVID-19 research (Barnett & Doubleday, 2021), and the rates of corrections and retractions (Moradi & Abdi, 2020).

In the first two months of the pandemic, Zhang et al. (2020) focused on past research on Zika, H1N1, Ebola, and SARS in response to World Health Organization public health emergency declarations and found spikes in article volume immediately following declarations. They also saw early upticks in COVID-19 research in pre-prints available on medRxiv and bioRxiv. Coccia (2021) also compared COVID-19 to Zika and H1N1, as well as MERS and HIV, but also analyzed COVID-19 in tandem with non-infectious respiratory disorders such as chronic obstructive pulmonary disease and lung cancer. This research ultimately suggested a framework that distinguishes between problem driven research fields (like lung cancer research) and crisis driven research fields (like COVID-19).

Several researchers have already used text mining and topic modeling to create an overview of research on COVID-19 (Cheng et al., 2020; Ebadi et al., 2020; Zhang et al., 2021). Cheng, Cao, and Liao (2020) compared COVID-19 topic models to MERS and SARS. They found that while there were similarities in the research on all three coronaviruses, COVID-19 research focused on the symptoms of patients and number of infections and cases, as opposed to the research at the cellular level around disease origins and antibodies for MERS and SARS. Their research shows the value in using text mining to provide a rapid "snapshot" for a specific field of study during a rapid increase in literature.

Ebadi et al. (2020) looked at structured topic models of articles on COVID-19 on PubMed and arXiv. They found significant differences in topic makeup on each database with arXiv articles being made up of more technical topics relating to detecting, diagnosing, or predicting the spread of COVID-19 and PubMed a much wider range of diverse topics with low similarity. This research was a key look at the differences in how one topic can be discussed across two different databases.

Zhang et al. (2021) looked at the effect of COVID-19 on coronavirus research generally, comparing topic models of pre and during COVID-19 articles. They found that COVID-19 disrupted existing lines of research and changed the makeup of topics in the field significantly. Using the scientific evolutionary pathways (SEP) process they tracked the evolution of topics over time and conducted statistical analyses to look at relationships between selected topics and topic affiliation types. They found that the topic communities "epidemiology" and "global health" both had larger proportions of emerging, new topics.

Thus far approaches to looking at the effect of COVID-19 on research have approached the phenomena by directly pulling articles specifically related to COVID-19 or comparison phenomena. This research uses previous methods, namely topic modeling, but takes a different approach and instead of looking at COVID-19 compared to other specific research phenomena, it looks at an entire topic area over time to see the emergence of COVID-19 as key research foci. This research also leverages a new database, NexisUni, to expand the view of the topic to include new legal contexts.

### *Contact Tracing and COVID-19*

Contact tracing is a routine public health process that involves identifying, managing, monitoring, and notifying people who have been infected with or exposed to a

particular infectious disease (World Health Organization, 2021). Contact tracing is not a novel public health tool. Physicians have been tracking the spread of infectious diseases through individual contact since at least the mid 16th century (Cohn & O'Brien, 2020). As germ theory emerged, so did more modern contact tracing. Specially trained sanitary inspectors who interviewed individuals and surveilled the spread of infectious diseases were even prevalent in the United Kingdom in the mid 19th century (Mooney, 2020). Although its form has changed over the centuries in response to new technologies including rapid testing, telephones, and even GPS, contact tracing still functions much in the same way it always has.

Since the COVID-19 pandemic, interest in contact tracing has exploded. As of March 2022, over 1,300,000 individuals had enrolled in the Johns Hopkins free COVID-19 Contact Tracing Coursera course. Not only has public interest in contact tracing grown, but research published on contact tracing has increased exponentially. While 230 scientific academic articles and 6 legal academic articles on contact tracing were published in 2019, in 2020 those numbers leapt to 864 and 49 respectively (See *Figure 4.1*). Prior to 2020, the most articles on contact tracing published in a given year were 273 articles on SCOPUS and 10 articles on NexisUni in 2015.

### *Topic Modeling and LDA*

Topic modeling has been applied across a wide range of fields, from medical communication (Kherwa & Bansal, 2022) to social media communication (Villa et al, 2021) to political science (Perlstein & Verboord, 2021). Topic modeling is a form of text mining that uses words or phrases to illustrate potential underlying structures or relationships in the corpus of documents (Yau et al., 2014). Fundamentally, text mining

identifies and explores patterns from the unstructured text in a document collection (Feldman & Sanger, 2007).

These text mining techniques generate groupings of words called topics. Topic modeling requires three basic components: (1) documents, which can be any form of text – from article abstracts to emails to chapters in a novel; (2) words, which are the individual terms that make up each document; and (3) the corpus, which is a set of documents, be they articles, emails, or chapters in a book. Latent Dirichlet allocation, or LDA is a specific technique for topic modeling developed by Blei et al. in 2003 and their original article explaining the technique has been cited by nearly 40,000 other researchers. LDA will be explained further in the methods section.

Legal scholars have begun to use topic modeling and LDA as well. Legal researchers have applied LDA to do a variety of analyses, including looking at the broad contours of all contractual good faith judicial opinions (Fagan, 2020), corporate veil piercing (Macey & Mitts, 2014), and bias in published US appellate court opinions (Carlson et al., 2020). Legal researchers have even investigated the change in topics across a sample of US Supreme Court opinions from 1951-2007 (Livermore et al., 2017).

In the field of scientometrics, LDA has been widely applied to illustrate the gaps between scientific fields (Yau et. al., 2014), map hot areas of research such as assisted reproductive technologies (Garcia et al., 2020), and delineate knowledge structure transition with specific fields (Miyata et al., 2020; Wu et al., 2019). Legal academic documents, however, have not been included in these analyses.

The reasons for the lack of inclusion are several. Firstly, legal academic articles are housed in different databases that are generally not accessible to non-legal scholars: WestLaw (Thompson Reuters) and LexisNexis (RELX formerly Elsevier). These

databases require a separate subscription, and many universities and libraries limit their access to those affiliated with the university's law school. NexisUni, a broader academic product offered by RELX, is more commonly available through standard university libraries.

Secondly, legal academic articles use different formatting for both the document and citations. Legal academic articles use footnotes for citations and require them to be in BlueBook style, a proprietary legal citation system that is significantly different from APA, Chicago Style, or AMA style. BlueBook style does not use a reference list, and legal academic journals do not use and themselves rarely have DOIs (Craigle, 2021). These factors make it challenging to incorporate legal academic article data in scientometric analyses that use either citations or document text.

**Research Questions**

This research uses LDA to illustrate the landscape of research on a specific public health topic: contact tracing. It also looks at changes in topics over time and reveals the effect of the COVID-19 research boom on contact tracing as a domain of research. It also offers a window into the thematic relationship between scientific academic publications and legal academic publications by incorporating articles across databases.

This research will build on past research on how COVID-19 is affecting the overall research landscape by looking at how the knowledge structure of an entire public health discipline changes not only across time periods, but also across databases. The research questions for this study are as follows:

(1) How do to topics in an existing public health field transition across the research periods?

(2) What is the position of articles from a legal academic database in the corpus as a whole and across time periods?

I used SCOPUS for scientific academic articles and NexisUni for legal academic articles because they are both owned by the same parent company RELX. This research also looks at a very narrow public health domain: contact tracing. By looking at a specific domain, this research will enable clearer elucidation of the small shifts in topics over time and the relationship between scientific academic article topic distributions and legal academic topic distributions.

In addition to looking at the corpus of publications as a whole, this research divides the dataset into six time periods based on decades, as opposed to preconceived ideas about shifts in the body of literature. The time periods were delineated as 1946 to 1979, 1980 to 1989, 1990 to 1999, 2000 to 2009, 2010 to 2019, and 2020. The time periods and article data are available in *Table 4.1*.

## Methods

### *Data Collection*

The data used for topic modeling were derived from both SCOPUS and NexisUni databases. All articles that matched the search term "contact tracing" were pulled. On the SCOPUS database all articles or reviews with the search term present in the article title, abstract, or keywords for all years were elicited. This initial search yielded 5,687 documents. 1209 articles had no abstracts available and were removed from the corpus. For NexisUni, all 264 law review articles containing the search term were retrieved. With the removal of duplicates, documents without an English translation, documents that were panel transcripts, legal news periodicals, and documents missing abstracts, the final corpus was 4885 articles.

### *Data Processing*

The SCOPUS article data were downloaded in a CSV file and abstracts were extracted into individual text files using a custom Python script (available on GitHub). Abstracts were used as opposed to full text because the analysis sought broad topics, and there was only a small benefit of topic modeling on full texts for a dataset of this size as opposed to abstracts (Syed & Spruit, 2017). Additionally, the added labor and complications in obtaining and cleaning full texts from both SCOPUS and NexisUni meant the use of abstracts allowed for more efficient data collection and cleaning. NexisUni articles were downloaded as 3 RTF files of no more than 100 articles each containing the metadata, entire article text, and citations for the articles.

The RTF files were converted into a standard text file, and then a Python script was used to separate each article into individual text files. Each article text file was hand cleaned down to abstracts without titles. All article text files from both SCOPUS and NexisUni were preprocessed using Automap to remove pronouns, numbers, prepositions, and stopwords, as well as convert all words to lower case.

Following Automap cleaning, additional cleaning using a custom Python script removed artifacts such as extra spaces between words from the Automap cleaning and reduced some bigrams (words that appear next to each other that incorporate one concept) commonly found in the corpus (e.g. New Zealand became newzealand). Other bigrams and n grams were not reduced and appear as separate terms in the topics (e.g. Ebola virus disease each appear as individual words despite being the full terminology for the disease).

The data were then divided into subsets based on the year of publication. Six subsets were created representing articles from 1946 to 1979, 1980 to 1989, 1990 to

1999, 2000 to 2009, 2010 to 2019, and 2020. Since each time slice has a different amount of articles, I also pulled normalized samples from each subset. The normalized subsets provided very similar topics to the non-normalized full dataset and so to maintain detail, the full set of articles for each subset were used.

### *Data Analysis*

LDA uses a "bag of words" approach; the order or proximity of words do not matter, only their frequency and that they co-occur in the same document. LDA uses all words across a corpus of texts to generate topics based on a Bayesian probabilistic model. Since LDA assumes that all words in the corpus are included in at least one topic, the number of topics must be selected by researchers at the outset. LDA assumes each topic is a distribution over words and assigns each word a frequency within a topic. This means words can occur in multiple topics.

The output from an LDA analysis is a list of topics with which words make up a large proportion of each topic listed as well as a list of documents with proportion of how much of each topic is represented in the document.

LDA was performed on the complete corpus using MALLET. For the complete corpus, I explored 15, 20, 25, 30, 35, and 40 topics. I determined that 25 topics offered the most salience without becoming overly simplified or too complicated. I then performed LDA on each of the data subsets. For data subsets, I explored topics settings from 5 to 10 and determined that while key concepts emerged from the corpus even at 5 topics, 7 topics offered distinct themes, while 10 topics offered increased complexity and diminished returns of coherence.

A separate script was then used to arrange the data into a distribution of topics across each article. This topic distribution grid allows us to see the percentage of each

article that is made up of each topic, with all of the topics adding up to 100% of the content of the article. This data was imported into ORA, a network analysis software developed by Center for Computational Analysis of Social and Organizational Systems (CASOS) at Carnegie Mellon. In ORA, I folded the articles into a multidimensionally scaled network that generates links between the articles and topics based on the percent of each article that is made up of each topic. ORA uses this calculation to visualize the networks. Topics and articles are each represented by a node. Edges between topics and nodes represent the connection between the article and the topic. The presence of a given topic in an article at a certain percentage (at least 14-20%, depending on the data subset) is represented by a line. The color of the node reflects whether the article is from the SCOPUS or NexisUni database.

To label the topics, I looked at the terms in the topic to come up with an initial code for what the topic was about. Based on my familiarity with the corpus, these initial impressions were a clear starting point. I then looked at the title and abstract for the top 5 articles with the highest percent of the topic represented and assessed them for similarities and differences. For example, if all 5 articles were articles about gonorrhea, it was likely the topic was about that specific infection. I then looked at several other articles containing lower percentages of the topic, including at least one article containing as little as 10% of a given topic to confirm the similarities and potential differences before assigning a label to the topic. All topics in both the full corpus and 6 subsets were labeled using this process.

## Results

### *Full Corpus*

*Table 4.2* provides the topics, the number of articles containing at least 20% of the topic, and the list of terms in the topic for the full corpus. The topic model shows that specific diseases make up a significant number of topics. STIs, HIV/AIDS, Tuberculosis, SARS, Ebola, and COVID-19 each are present as distinct topics. In addition to the name of each of these distinct diseases, the topics also include other key words specific to the research discourse around each illness. For example, the topic HIV/AIDS contains the terms "status" and "transmission," and is the only topic to contain the term "prevention." The topic Ebola contains the terms "Africa" and "outbreak." The Tuberculosis topic contains technical terms for specific TB testing methods including the abbreviations for tuberculosis skin test (TST) and the QuantiFERON-TB Gold (QFT) blood test. A sample of articles containing high distributions of the topic Tuberculosis can be seen in *Table 4.3*. The COVID-19 topic contains the terms "social," "distancing," and is the only topic to contain the term "pandemic." A sample of articles containing high distributions of the topic COVID-19 can be seen in *Table 4.4*.

Several topics, such as the Paper Methods – Descriptives, Paper Methods – Population of Study, Methods – Findings, and Paper Methods – Statistics topics, are made up of terms that are used frequently across many of the articles to discuss the structure of the research or results. These topics tended to be present in low distributions in a large number of the articles in the corpus, but only highly present in a small number of papers. For example, the topic Methods – Statistics made up 20% or more of 67 articles, but made up at least 10% of 432. Similarly, Paper Methods –

Descriptives and Paper Methods – Population of Study only made up 20% or more of 7 articles each, but made up at least 10% of 96 and 104 articles, respectively. The paper with the highest proportion of the topic Methods – Statistics was a paper about the risk assessment of venous thromboembolism that involved technical reporting of the statistical calculations used in the abstract. A sample of articles containing high distributions of the topic Methods – Statistics can be seen in *Table 4.5*. These "Paper Methods" topics are all made up of themes related to the description of research and results, as opposed to the primary topic of a given paper. The nature of these topics is perhaps why they appear across many articles, but only make up a small proportion of any given document.

Other topics refer not to a specific disease, but an area of concern across diseases for contact tracing. These topics include Hospitals, Treatment, Digital Surveillance, Treatment, Modeling, and Contact Elicitation.

Articles from NexisUni showed a heavy presence of topics from three primary topic areas: Confidentiality and the Law, Public Health Authority, and Public Health Organizations. The Confidentiality and the Law topic included the terms "law," "legal," "policy," "confidentiality," and "legislation." It seems obvious that articles in legal academic journals would include a heavy proportion of language about "law" and "policy," but it is interesting that this topic's first term is "AIDS." This is likely because a large proportion of the research on confidentiality occurred in response to the HIV/AIDS pandemic during the 1980s and the 1990s. A sample of three articles containing high distributions of this topic can be seen in *Table 4.6*.

The Network visualization of the full contact tracing corpus in *Figure 4.2* shows a 2D plot of the relationships between the articles based on similarity of topic distribution.

Articles are linked via lines to the topics which make up the highest proportion of their language. For visual clarity, links between articles and topics with a weight of less than 0.16, or 16% of the paper were removed. This visualization shows clustering of the NexisUni articles around the topics of Public Health Authority, Confidentiality and the Law, and Public Health Organizations. There are some additional links between NexisUni articles and Digital Surveillance, Contact Tracing Methods, and Expedited Partner Theory, as well as the two large disease topics of COVID-19 and HIV/AIDS. As predicted, articles from legal academic databases are thematically distinct from scientific academic articles and they occupy a polarized space in the contact tracing corpus network.

***Changing Topics Over Decade Subsets***

*Table 4.7* through *Table 4.12* provide the topics, the number of articles containing at least 20% of the topic, and the list of terms in the topic for each of the time-delineated subsets of the corpus. By breaking the corpus into time slices, the changes in the topics over time are visible.

While a topic model of the full corpus showed the presence of disease-based topics, the decade time slices show when these diseases emerged as significant drivers in the research. In the first time slice, 1946 to 1979, sexually transmitted diseases including syphilis and gonorrhea are the specific disease concern. Tuberculosis is present as a term in the topic on Clinical Management, but is not significant enough to make up its own topic. In 1980 to 1989, Syphilis and gonorrhea remain a concern, but HIV/AIDS research has expanded to create two topics, one focusing on transmission and another on confidentiality. Tuberculosis now has its own topic as well. In the 1980 to 1989 time slice a Law and Control topic also appears containing the terms “control,” “prevent,”

"compulsory," "order," and "prison." As with the Law and Confidentiality topic for the entire corpus, this initial legal topic contains the term "AIDS" as well.

In the 1990 to 1999 time slice gonorrhea and syphilis was subsumed into a broader STDs topic including chlamydia. HIV and Confidentiality persists as a topic, as does Tuberculosis. A new topic around Partner Notification appears. Instead of a topic focused on the law and mandates, another topic that contains the terms "health," "public," "law," "legal," "risk," and "rights" appears labeled Advocacy.

In the 2000 to 2009 time period, Tuberculosis remains, as does Partner Notification. Chlamydia emerges as the STD of the decade and another topic containing the terms "model," "transmission," "data," and "spread" occurs. The legal topic shifts again, this time away from advocacy to Surveillance, with the terms "law," "surveillance," "legal," "response," and "policy." SARS appears as a term, but does not appear to dominate a topic as it does in the full corpus.

In the 2010 to 2019 subset, Tuberculosis remains, as well as Partner Notification, and Modeling. The legal topic Law and Policy still retains the term "surveillance," but no longer contains the term AIDS. A topic that focuses on Transmission in Hospitals appears, as does a separate topic on Interventions and Efficacy.

In the year 2020, COVID-19 emerges not only as a stand-alone topic but as a driver of the other topics, including Surveillance, Global Epidemiological Response, Digital Contact Tracing, and Healthcare Workers and Hospitals. The topic Case Studies contains the terms "tuberculosis" and "HIV" and articles with a high distribution of this topic are the minority of the subset that are not specifically about COVID-19.

As with the full corpus, *Figure 4.4* through *4.8* show a 2D plot of the articles in each subset linked to the topics which make up the highest proportion of their content.

For visual clarity, links between articles and topics where the topic represented less than 14% to 21% of the article removed depending on the dataset.

These visualizations show the presence of a NexisUni legal article cluster consistently through each decade. They show the cluster of NexisUni legal articles largely centered around the key legal topic of each time slice, from Law and Control to Advocacy to Law and Surveillance. Additionally, they show the closeness between the legal cluster and the HIV and Confidentiality topic in the 1980 to 1989 and 1990 to 1999 time slice. They also show the adjacency of Law and Surveillance to Partner Notification in the 2000 to 2009 subset. As with the full corpus, the legal academic database articles cluster around distinct themes and occupy a distinct space from scientific academic articles.

**Discussion**

For research question 1, regarding the kinds of transitions seen across the different research periods among topics, this research found that some topics remain largely consistent across one of more time periods. These consistent topics include Tuberculosis, which appears as a term in the 1964 to 1979 dataset topic Clinical Management and emerges as a larger topic present in a large proportion of the research in the 1980 to 1989 dataset. Tuberculosis stays a significant topic until 2020, when COVID completely dominates the subset.

Other topics like gonorrhea, syphilis, and chlamydia shift over the time subsets as different STDs dominate the research discourse in each decade. Public health techniques, like Partner Notification appear in the 1990 to 1999 time subset and remain through the 2000 to 2009 and 2010 to 2019 subsets.

As noted by other researchers, including Fassin (2021), COVID-19 emerges as a dominating force in 2020. Not only is the 2020 data subset larger than the decade-long 1990 to 1999 subset, but it is also comparable in size to the 2000 to 2009 and 2010 to 2019 decade subsets. Looking at the entire corpus, it appears that contact tracing topics do become dominated by certain diseases du jour. While COVID-19 certainly is the hot topic of 2020, the full corpus and data subset show that each decade seems to have at least one disease that overtakes the discourse. For 1964 to 1979 it was gonorrhea, for the 1980s and 90s it was HIV/AIDS, for the 2000s and 2010s it was tuberculosis. Looking at the entire corpus the major diseases are each represented by their own topic area: tuberculosis, HIV/AIDS, SARS, Ebola, and COVID.

This prominence of novel or resurging disease topics builds on Zhang et al. (2021)'s findings that topic communities around epidemiology and global health have a higher proportion of emerging topics than other topic communities like infectious disease research or immune response. Public health practice research is characterized by responses to contagious diseases, therefore it makes sense that the field would have one "hot" topic that changes over time as the primary disease of concern changes.

For research question 2 regarding the relationship between the topics and databases, there is a clear relationship between the NexisUni legal articles and specific topics in each time period. Each time slice has a single topic where a large proportion of legal articles cluster that also contains the terms "law" and "legal." While many of the other topics remain consistent across each decade, the content of the primary legal topic morphs significantly over each time slice. Despite this, the legal cluster is clearly visible. Legal articles remain linguistically distinct from scientific articles in both the entire corpus and across each time slice.

The shifts in the legal discussion over each time subset offer insight into the thrust of the legal discussion around disease in each decade. In the 1980 to 1989 subset, articles with high proportions of the legal topic "law and control" frame discussion in terms of "control," and "compulsory," by the 1990 to 1999 time slice the legal topic and related articles seems to have shifted significantly to focus instead on advocacy and rights. By 2000 to 2009 and through 2010 to 2019, surveillance seems to be a key concept in the legal topic. For the 2020 dataset, surveillance has emerged as its own topic with law as just a term within it. The legal articles still cluster primarily around "Surveillance" and "Digital Contact Tracing" with only a few clustering near Global Epidemiological response and Healthcare Workers and Hospitals.

The introduction of legal academic papers into the corpus shifted the topics and shows that the discussions in legal academic literature focus heavily on control and surveillance. While legal academic articles may not significantly shift the topics of every corpus, in certain topic areas, like public health practice there are significant concerns and discussion of both policy pathways and policy ramifications of research. Adding legal academic articles into the corpus can expand the view of a field and allow researchers to see on which areas policy influences may be focusing.

Overall, the field of contact tracing has not innovated significantly over time. The topics show some minor changes in methodology over time, but the primary drivers in each time period are the primary contagious diseases of each decade and the subtle shifts in the primarily legal topic. Starting in the 1980s, the legal climate and privacy law has had a huge impact on contact tracing. Over time the legal climate around privacy, and the laws in place to either secure individual privacy or aid in population surveillance have shifted. In adding NexisUni legal academic articles to the corpus, instead of just the

SCOPUS scientific articles important trends that are crucial to understanding public health practice topics like contact tracing are visible.

**Limitations**

This paper has several limitations. Firstly, the data was collected from SCOPUS and NexisUni in mid 2021. Given the time delay in availability of articles on these databases, many articles from 2020 were not included in the corpus. As of March 2022, there are an additional 430 SCOPUS articles available published in 2020 and 1852 in 2021. NexisUni shows an additional 315 articles for 2020 and 2021.

Additionally, the term "contact tracing" is limited and likely excluded some number of relevant articles that covered the same concept but used different terminology, especially older articles written before 1964.

**Conclusion**

These results were based on an analysis of 4885 articles in both the SCOPUS and NexisUni databases. This research confirms much of the previous scientometric research that found COVID-19 to be a disruptive research phenomenon. In exploring the articles published across both SCOPUS and NexisUni databases on a general public health topic, specifically contact tracing, this research shows that COVID-19 has not only affected journals and overall citation metrics, but has fundamentally changed the topic makeup of a specific public health practice area. This research also builds off of Zhang et al.'s (2021) work on research responses to public health emergencies to show the topical specifics of how certain diseases dominate in given time periods.

The LDA analysis indicated that specific disease themes dominated the topics for each time period, and that certain topics remained consistent across multiple time periods like legal issues and partner notification. The articles from the legal academic

database, NexisUni, also consistently clustered together around the legal focused topic in each decade and remained thematically distant from articles in the SCOPUS database.

Further research could investigate the prevalence of COVID-19 across other public health practice topics, such as social distancing, isolation and quarantine. It is also important to continue to monitor the effect of COVID-19 and other emerging diseases on research. Further bibliometric and topic modeling analysis in one to two years might yield further insight into the effect this unique disease has had on research.

## Tables and Figures

*Figure 4.1: Articles on Contact Tracing by Database Over Time*

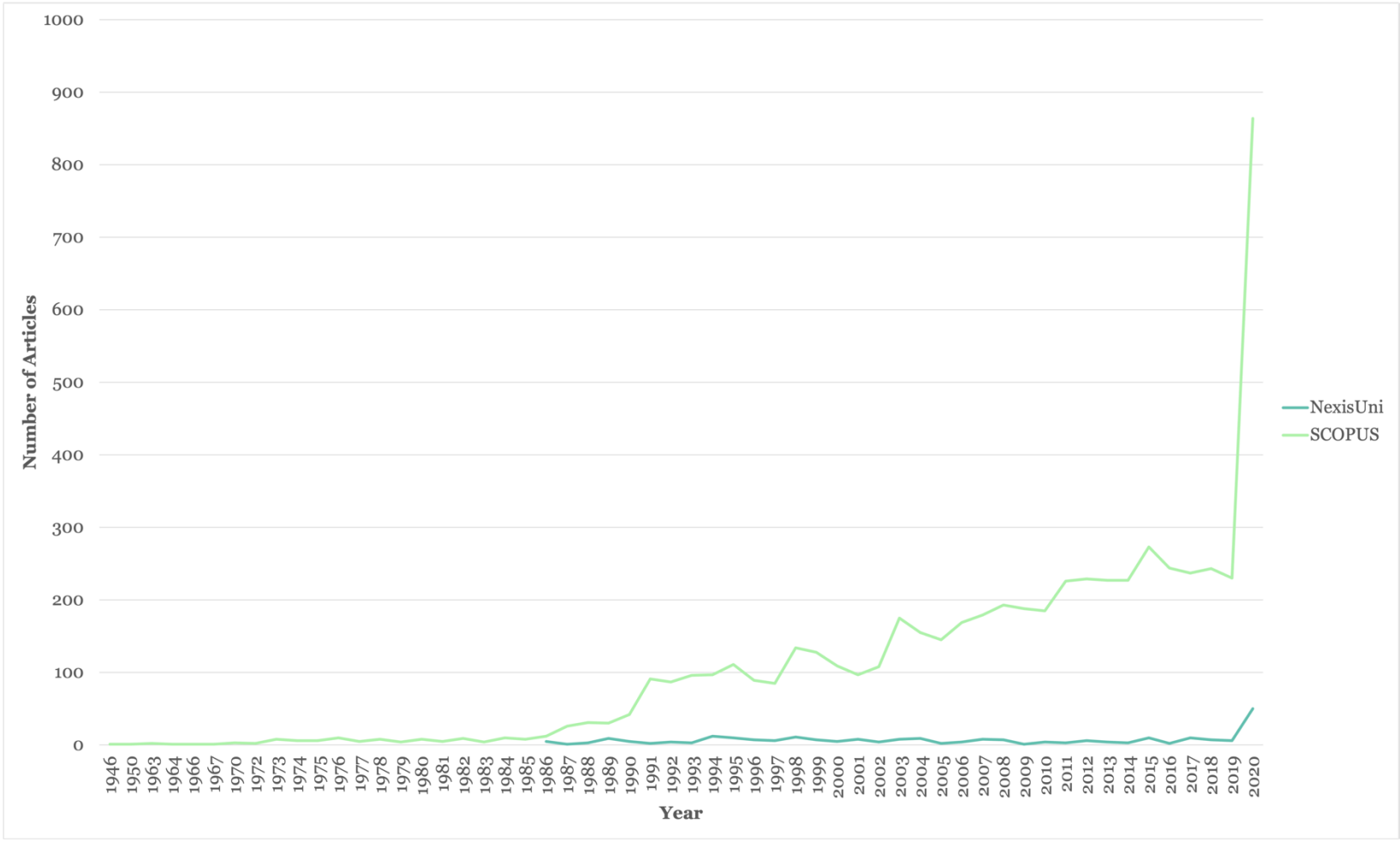


*Table 4.1: Number of Articles Per Database, Per Year Subset*

| Database | 1946-1979 | 1980-1989 | 1990-1999 | 2000-2009 | 2010-2019 | 2020 |
|---|---|---|---|---|---|---|
| SCOPUS | 42 | 85 | 618 | 1214 | 1995 | 702 |
| NexisUni | 0 | 18 | 66 | 55 | 54 | 37 |

*Table 4.2: Contact Tracing Corpus Topic Labels, Article Counts, and Terms*

| Topic Label | No. of Articles[25] | Topic Terms |
|---|---|---|
| Paper Methods - Descriptives | 7 \| 96 | based, high, population, level, low, potential, areas, time, due, current, area, long, levels, range, specific, large, considered, previous, term |
| Paper Methods – Population of Study | 7 \| 104 | Group, unknown, people, community, individual, groups, common, knowledge, role, focus, approach, work, good, time, control, history, place, including, problems |
| COVID-19 | 91 \| 378 | COVID, measures, pandemic, disease, social, spread, control, isolation, quarantine, early, effective, coronavirus, distancing, strategies, rapid, containment, implemented, physical, current |
| Paper Methods - Findings | 37 \| 206 | Study, studies, data, review, methods, evidence, identified, included, national, conclusions, conducted, guidelines, background, outcomes, objective, conclusion, quality, findings, assessment |
| HIV/AIDS | 123 \| 447 | HIV[26], testing, infected, persons, risk, positive, infection, test, tested, individuals, drug, prevention, immunodeficiency, status, virus, care, transmission, AIDS[27], newly |

[25] Number of Articles that have a prevalence of this topic above 20%|10%
[26] HIV is an abbreviation for Human Immunodeficiency Virus
[27] AIDS is an abbreviation for Acquired Immunodeficiency Syndrome.

| | | |
|---|---|---|
| Paper Methods - Statistics | 67 \| 432 | Risk, CI[28], study, factors, infection, compared, higher, methods, conclusions, ratio, characteristics, analysis, participants, background, interval, confidence, objective, age, odds |
| Tuberculosis | 320 \| 831 | TB[29], tuberculosis, positive, contacts, TST[30], active, test, infection, pulmonary, QFT[31], skin, smear, tuberculin, LTBI[32], latent, sputum, MDR[33], negative, chest |
| Treatment | 36 \| 378 | Patients, treatment, patient, care, clinical, diagnosis, follow, therapy, management, months, treated, health, medical, received, recommended, diagnosed, clinic, center, month |
| Transmission and Disease Genetics | 230 \| 457 | Transmission, patients, isolates, strains, epidemiological, analysis, clusters, tuberculosis, molecular, resistant, cluster, identified, outbreak, resistance, strain, MRSA[34], drug, typing, source |
| Confidentiality and the Law | 157 \| 376 | AIDS, law, legal, medical, rights, article, individual, issues, confidentiality, laws, policy, privacy, unknown, mandatory, public, legislation, ethical, protect, physicians |
| Hospitals | 122 \| 404 | Infection, hospital, patient, exposure, workers, staff, care, case, healthcare, outbreak, report, risk, control, fever, hospitals, exposed, source, HCWs[35], occurred |
| Digital Surveillance | 113 \| 310 | Data, surveillance, system, based, privacy, technology, paper, app, technologies, collection, digital, protection, systems, apps, mobile, approach, tools, individuals, personal |
| Contact Tracing Methods | 8 \| 174 | Contact, tracing, number, identification, method, period, delay, methods, infected, traced, order, evaluate, effective, findings, general, aimed, approach, time, proportion |
| Cost Effectiveness | 66 \| 308 | Screening, cost, program, effectiveness, effective, intervention, control, strategy, high, costs, strategies, interventions, settings, prevalence, impact, groups, based, reduce, finding |



[28] CI is an abbreviation for Confidence Interval
[29] TB is an abbreviation for tuberculosis.
[30] TST is an abbreviation for Tuberculosis Skin Test.
[31] QFT is an abbreviation for QuantiFERON-TB Gold, a blood test for tuberculosis.
[32] LTBI is an abbreviation for Latent TB Infection.
[33] MDR is an abbreviation for multi-drug resistant, usually used in conjunction with TB.
[34] MRSA is an abbreviation for Methicillin-resistant Staphylococcus aureus, a drug resistant strain of staph infection that is difficult to treat.
[35] HCWs is an abbreviation for healthcare workers.

| | | |
|---|---|---|
| Diagnosis | 109 \| 312 | Positive, leprosy, blood, tests, patients, detection, clinical, test diagnostic, negative, samples, diagnosis, PCR[36], Ct[37], specific, anti, early, reaction, sensitivity |
| Public Health Authority | 25 \| 140 | Government, federal, local, national, quarantine, response, support, emergency, authorities, provide, department, domestic, safety, enforcement, order, required, military, authority, security |
| Children | 71 \| 407 | Children, years, incidence, age, rate, year, cases, vaccination rates, disease, aged, high, adults, born, child, measles, population, adult, young |
| Modeling | 149 \| 424 | Model, epidemic, data, number, population, models, individuals, dynamics, time, based, estimated, DE[38], patterns, transmission, rate, distribution, modeling, estimate, interventions |
| STIs | 184 \| 619 | Men, women, infection, chlamydia, sexual, syphilis, infections, transmitted, sexually, STD[39], male, MSM[40], trachomatis, clinics, clinic, sex, gonorrhea, gonorrhoea, female |
| Ebola | 81 \| 303 | Countries, outbreak, community, control, Ebola, virus, disease, health, response, Africa, surveillance, management, EVD[41], prevention, outbreaks, local, implementation, epidemic, including |
| Public Health Organizations | 52 \| 287 | Health, public, united, international, disease, diseases, global, states, human, care, article, CDC[42], systems, communicable, policy, economic, departments, responses, services |
| Transmission and Social Networks | 91 \| 305 | Disease, transmission, network, infectious, spread, networks, social, control, risk, diseases, infected, individuals, students, outbreaks, large, human, school, highly, analysis |
| Contact Elicitation | 49 \| 471 | Cases, contacts, case, household, identified, total, investigation, detected, period, disease, diagnosed, close, confirmed, reported, number, family, high, rate, finding |



[36] PCR means polymerase chain reaction and is a type of test designed to detect genetic material from a specific organism such as a virus.
[37] Ct is an abbreviation for cycle threshold and refers to the number of cycles needed for the fluorescent signal in a PCR assay test to accumulate to indicate the positive presence of the sought-after genetic material in a test.
[38] DE is an abbreviation for differential equations.
[39] STD is an abbreviation for sexually transmitted disease.
[40] MSM is an abbreviation for men who have sex with men.
[41] EVD is an abbreviation for Ebola Virus Disease.
[42] CDC is an abbreviation for the Centers for Disease Control and Prevention.

| | | |
|---|---|---|
| Expedited Partner Therapy | 240 \| 542 | Partner, partners, notification, referral, PN[43], services, STI[44], sexual, sex, EPT[45], notified, interviews, reported, practice, participants, patient, provider, providers, methods |
| SARS | 141 \| 431 | SARS[46], days, transmission, COV[47], symptoms, respiratory, virus, infection, confirmed, influenza, severe, cases, acute, syndrome, outbreak, asymptomatic, day, illness, period |



[43] PN is an abbreviation for partner notification.
[44] STI is an abbreviation for sexually transmitted infection.
[45] EPT is an abbreviation for expedited partner therapy.
[46] SARS is an abbreviation for Severe Acute Respiratory Syndrome.
[47] COV is an abbreviation for coronavirus.

*Table 4.3: Sample of Articles with High Distributions of the topic Tuberculosis*

| **Topic Proportion** | **Authors** | **Title** | **Database** | **Journal** | **Discipline**[48] |
|---|---|---|---|---|---|
| 0.46 | Verhagen L.M., et al. | Agreement between QuantiFERON®-TB Gold In-Tube and the tuberculin skin test and predictors of positive test results in Warao Amerindian pediatric tuberculosis contacts | SCOPUS | BMC Infectious Diseases | Medicine: Infectious Disease |
| 0.09 | Johns, K.A., & Varkoutas, C. | The Tuberculosis Crisis: The Deadly Consequence of Immigration Policies and Welfare Reform | NexisUni | Journal of Contemporary Health Law & Policy | Law |
| 0.1 | Li J., et al. | Human immunodeficiency virus counseling, testing, and referral of close contacts to patients with pulmonary tuberculosis: Feasibility and costs | SCOPUS | Journal of Public Health Management and Practice | Medicine: Health Policy |



[48] Based on SCOPUS Subject Areas.

*Table 4.4: Sample of Articles with High Distributions of the topic COVID-19*

| Topic Proportion | Authors | Title | Database | Journal | Discipline |
|---|---|---|---|---|---|
| 0.46 | Ngonghala C.N., et al. | Mathematical assessment of the impact of non-pharmaceutical interventions on curtailing the 2019 novel Coronavirus | SCOPUS | Mathematical Biosciences | Applied Mathematics |
| 0.31 | Thomas A. Baker, et al. | COLLEGE FOOTBALL IN THE TIME OF COVID-19 | NexisUni | Wisconsin Law Review | Law |
| 0.25 | Chakraborty I., Maity P. | COVID-19 outbreak: Migration, effects on society, global environment and prevention | SCOPUS | Science of the Total Environment | Environmental Science |

*Table 4.5: Sample of Articles with High Distributions of the topic Methods – Statistics*

| Topic Proportion | Authors | Title | Database | Journal | Discipline |
|---|---|---|---|---|---|
| 0.38 | Reed C.R., et al. | Contact isolation is a risk factor for venous thromboembolism in trauma patients | SCOPUS | Journal of Trauma and Acute Care Surgery | Medicine |
| 0.26 | Chatterjee P., et al. | Healthcare workers & SARS-CoV-2 infection in India: A case-control investigation in the time of COVID-19 | SCOPUS | Indian Journal of Medical Research | Biochemistry |
| 0.11 | Fiske C.T., et al. | Risk factors for treatment default in close contacts with latent tuberculous infection | SCOPUS | International Journal of Tuberculosis and Lung Disease | Medicine |

*Table 4.6: Sample of Articles with High Distributions of the topic Confidentiality and the Law*

| **Topic Proportion** | **Authors** | **Title** | **Database** | **Journal** | **Discipline** |
|---|---|---|---|---|---|
| 0.6 | William F. Flanagan | Genetic Data and Medical Confidentiality | NexisUni | Health Law Journal | Law |
| 0.41 | Harold Edgar, Hazel S. Omire | Medical Privacy Issues In The Age Of AIDS: Legislative Options | NexisUni | American Journal of Law & Medicine | Law |
| 0.33 | Jayawardena H. | AIDS and Professional Secrecy in the United States | SCOPUS | Medicine, Science and the Law | Medicine: Health Policy |

*Figure 4.2: Network Visualization of the Contact Tracing Corpus*

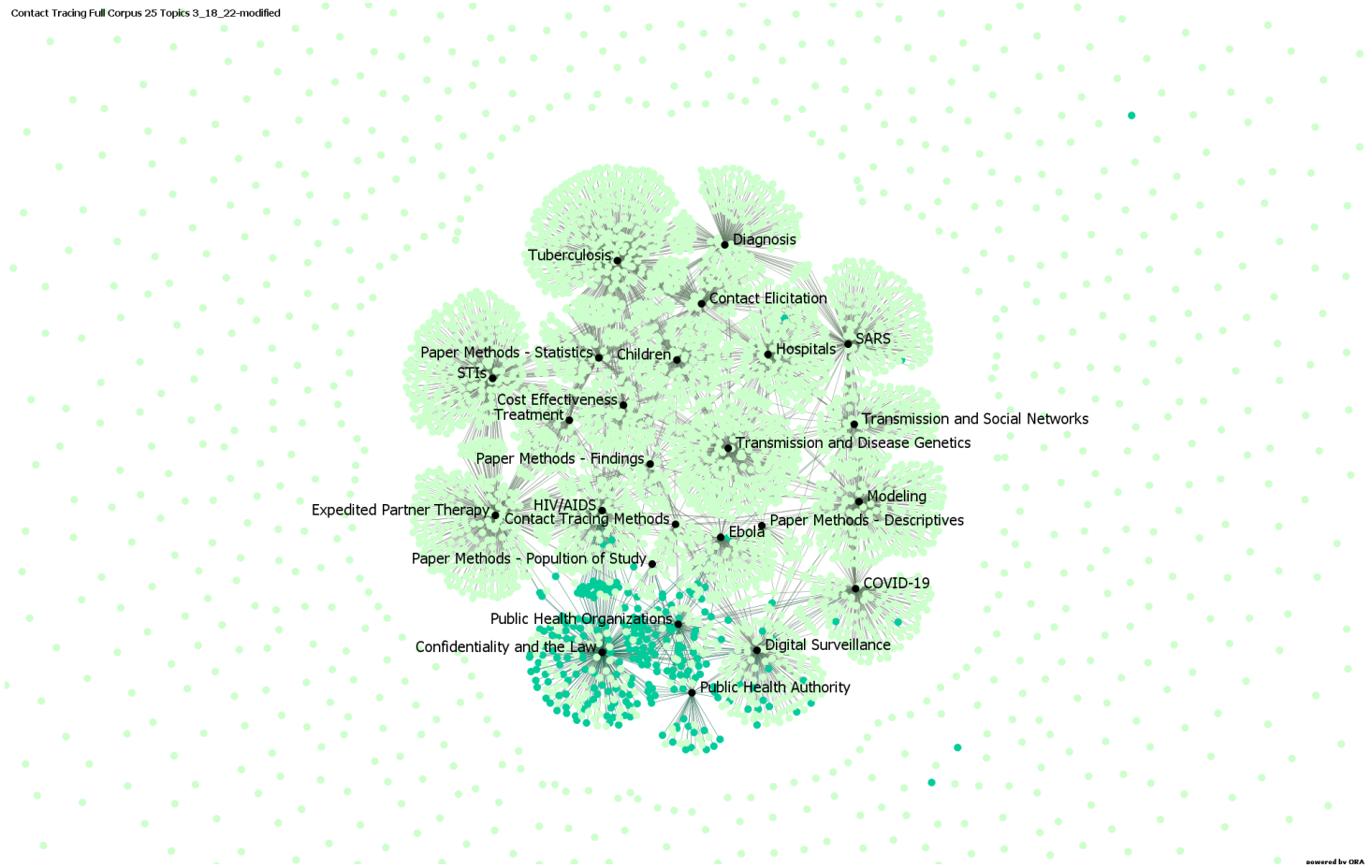


*Table 4.7: Topic Label, Articles, and Terms in 1946-1979*

| Topic Label | No. of Articles at least 20% | Topic Terms |
|---|---|---|
| Practitioner Case Studies | 5 | Disease, clinics, venereal, public, group, case, physicians, program, private, areas, interview, increasing, detection, procedures, adequate, hospital, general, review, common |
| Contact Tracing Processes | 9 | Contact, tracing, patients, contacts, increase, female, facilities, sex, patient, system, years, efforts, committee, occurred, analyzed, care, problems, provided, detected, |
| Gonorrhea | 7 | Gonorrhea, men, women, infected, diagnosis, gonococcal, reported, infection, sexual, anorectal, symptoms, cultures, homosexual, age, cent, resources, tests, activity, major, |
| Clinical Management | 4 | Cases, high, area, activities, notified, examination, Scotland, tuberculosis, country, data, situation, united, incidence, numbers, males, investigation, population, Pakistanis, improved |
| Regional Case Studies | 5 | Treatment, leprosy, rate, increased, study, male, time, penicillin, effective, period, epidemiological, early, Okinawa, policy, percentage, asymptomatic, screening, year, dose, |
| Sexually Transmitted Diseases 1 | 4 | Health, VD[49], education, incidence, countries, workers, considered, services, diagnostic, groups, large, discussed, England, Canada, center, management, programs, STD[50], laboratory |
| Sexually Transmitted Diseases 2 | 6 | Diseases, control, syphilis, gonorrhoea, sexually, transmitted, number, methods, clinic, field, international, factors, training, prevention, ophthalmia, infections, special, European, spread |



[49] VD is an abbreviation for venereal disease.
[50] STD is an abbreviation for sexually transmitted disease.

*Table 4.8: Topic Label, Articles, and Terms in 1980-1989*

| Topic Label | No. of Articles at least 20% | Top 5 Terms |
|---|---|---|
| STD Case Studies | 22 | contact, tracing, diseases, sexually, transmitted, control, population, STD, groups, study, rate, genital, STDs, areas, include, leprosy, major, infectious, prevention |
| Gonorrhea and Syphilis | 17 | Cases, tracing, PPNG[51], male, syphilis, incidence, infections, strains, trachomatis, gonorrhoeae, female, early, plasmid, Neisseria, increased, homosexual, days, gonococcal, isolated |
| HIV and Transmission | 11 | Health, virus, group, infection, education, policy, human, syndrome, acquired, deficiency, people, immune, evidence, person, common, action, social, immunodeficiency, hepatitis |
| HIV and Confidentiality | 12 | HIV[52], health, patient, infected, patients, risk, sexual, unknown, care, physicians, infection, confidentiality, partners, persons, test, physician, duty, individual, article |
| Tuberculosis | 19 | Disease, tuberculosis, effective, children, cases, case, years, treatment, reported, diagnosis, general, contact, drug, therapy, pulmonary, diagnosed, community, symptoms, year |
| Gonorrhea and Chlamydia | 20 | Patients, contacts, gonorrhea, positive, women, men, treatment, screening, infection, treated, high, clinic, gonorrhoea, follow, chlamydia, prevalence, clinics, cost, chlamydial |
| Law and Control | 13 | AIDS[53], public, law, medical, spread, health, legal, measures, transmission, control, prevent, note, epidemic, carriers, compulsory, order, issues, prison, rights |



[51] PPNG is an abbreviation for penicillinase-producing Neisseria gonorrhoeae, a strain of penicillin resistant gonorrhea.
[52] HIV is an abbreviation for Human Immunodeficiency Virus.
[53] AIDS is an abbreviation for Acquired Immune Deficiency Syndrome.

*Table 4.9: Topic Label, Articles, and Terms in 1990-1999*

| Topic Label | No. of Articles at least 20% | Top 5 Terms |
|---|---|---|
| Case Studies | 120 | patients infection patient risk transmission hospital infected identified case exposure workers outbreak staff clinical guidelines positive procedures virus performed |
| Tuberculosis | 182 | tuberculosis cases contacts TB[54] disease positive contact case children screening years test high skin pulmonary investigation infectious active study |
| Partner Notification | 132 | notification partner partners sexual group men persons risk reported prevention sex program based effective control infected number programs high |
| HIV and Confidentiality | 135 | HIV AIDS testing health test confidentiality positive public mandatory policy infected issues care status privacy physicians individuals legislation virus |
| Interventions and Blood Products | 35 | blood community drug group government national time militia united countries system unknown members role constitutional paper groups service control |
| Advocacy | 88 | health public unknown law medical care individual disease social people epidemic group legal risk current treatment rights model spread |
| STDs | 150 | contact treatment tracing women infection study STD transmitted data population sexually chlamydia infections clinic years age general gonorrhoea rate |



[54] TB is an abbreviation for tuberculosis.

*Table 4.10: Topic Label, Articles, and Terms in 2000-2009*

| Topic | No. of Articles at least 20% | Top 5 Terms |
|---|---|---|
| Tuberculosis | 284 | TB contacts tuberculosis positive children infection contact test TST[55] patients years CI[56] active household case age risk tuberculin rate |
| Chlamydia | 252 | treatment screening infection chlamydia patients patient clinic management cost men prevalence follow women program treated trachomatis therapy clinics effective |
| Modeling and Interventions | 198 | contact tracing disease data control number based epidemic model population transmission infectious spread network time networks vaccination level social |
| Law and Surveillance | 152 | health public law surveillance AIDS legal unknown medical individual national article system international global support united response policy group |
| Partner Notification | 273 | HIV partners partner sexual notification infected testing sex transmitted syphilis sexually study unknown women reported men risk group diagnosed |
| Outbreaks and Case Studies | 223 | cases case SARS[57] outbreak patients care infection hospital patient disease period days clinical measures early workers control respiratory symptoms |
| Microbiology | 215 | cases patients transmission contact identified methods incidence epidemiological study analysis tuberculosis high isolates tracing source case investigation detected strains |



[55] TST is an abbreviation for tuberculosis skin test.
[56] CI is an abbreviation for confidence interval, which is frequently reported in articles alongside discussion of tuberculosis tests, especially when comparing between tests.
[57] SARS is an abbreviation for Severe Acute Respiratory Syndrome.

*Table 4.11: Topic Label, Articles, and Terms in 2010-2019*

| Topic | No. of Articles at least 20% | Top 5 Terms |
|---|---|---|
| Interventions and Efficacy | 349 | tracing screening case high control treatment strategies effective studies program health cost effectiveness based national contact strategy settings incidence |
| Law and Policy | 224 | health public unknown group disease international quarantine united countries law people global diseases states response human surveillance policy individual |
| Modeling | 322 | contact data transmission model network based individuals number time population tracing disease social infected spread contacts infectious epidemic networks |
| Transmission in Hospitals | 390 | cases patients transmission identified infection study leprosy clinical tracing hospital epidemiological patient analysis source case isolates methods contact investigation |
| Tuberculosis | 561 | TB contacts tuberculosis children positive cases household risk patients contact years infection active CI test study TST QFT[58] treatment |
| Partner Notification | 455 | HIV partner partners notification testing sexual care treatment men patients patient sex syphilis reported chlamydia participants STI methods women |
| Case Studies | 386 | outbreak cases control virus case Ebola disease measures vaccination outbreaks infection days influenza confirmed EVD[59] community reported measles workers |



[58] QFT is an abbreviation for QuantiFERON TB test, which is a blood test used in diagnosing tuberculosis.
[59] EVD is an abbreviation for Ebola virus disease.

*Table 4.12: Topic Label, Articles, and Terms in 2020*

| **Topic** | **No. of Articles at least 20%** | **Top 5 Terms** |
|---|---|---|
| Surveillance | 87 | data unknown group public privacy surveillance individuals individual technology technologies personal protection people governments emergency pandemic rights collection law |
| Global Epidemiological Response | 144 | health pandemic Covid public countries response community global people disease management human international challenges virus policy south systems role |
| COVID | 196 | cases SARS COV Covid patients coronavirus case transmission disease confirmed days infection symptoms respiratory close asymptomatic severe testing China |
| Digital Contact Tracing | 147 | contact tracing data based Covid app digital apps studies developed study system approach paper privacy methods large current mobile |
| Social Models of Control | 156 | measures number social control model transmission distancing epidemic tracing isolation population contact testing effective quarantine disease strategies outbreak lockdown |
| Healthcare Workers and Hospitals | 75 | Covid care patient outbreak including spread healthcare virus workers medical risk prevention control rapid diseases prevent hospital potential person |
| Case Studies | 125 | contacts TB contact study infection patients cases CI tuberculosis treatment years household HIV screening methods identified age risk children |

*Figure 4.3: Network Visualization of Articles from 1946 to 1979*

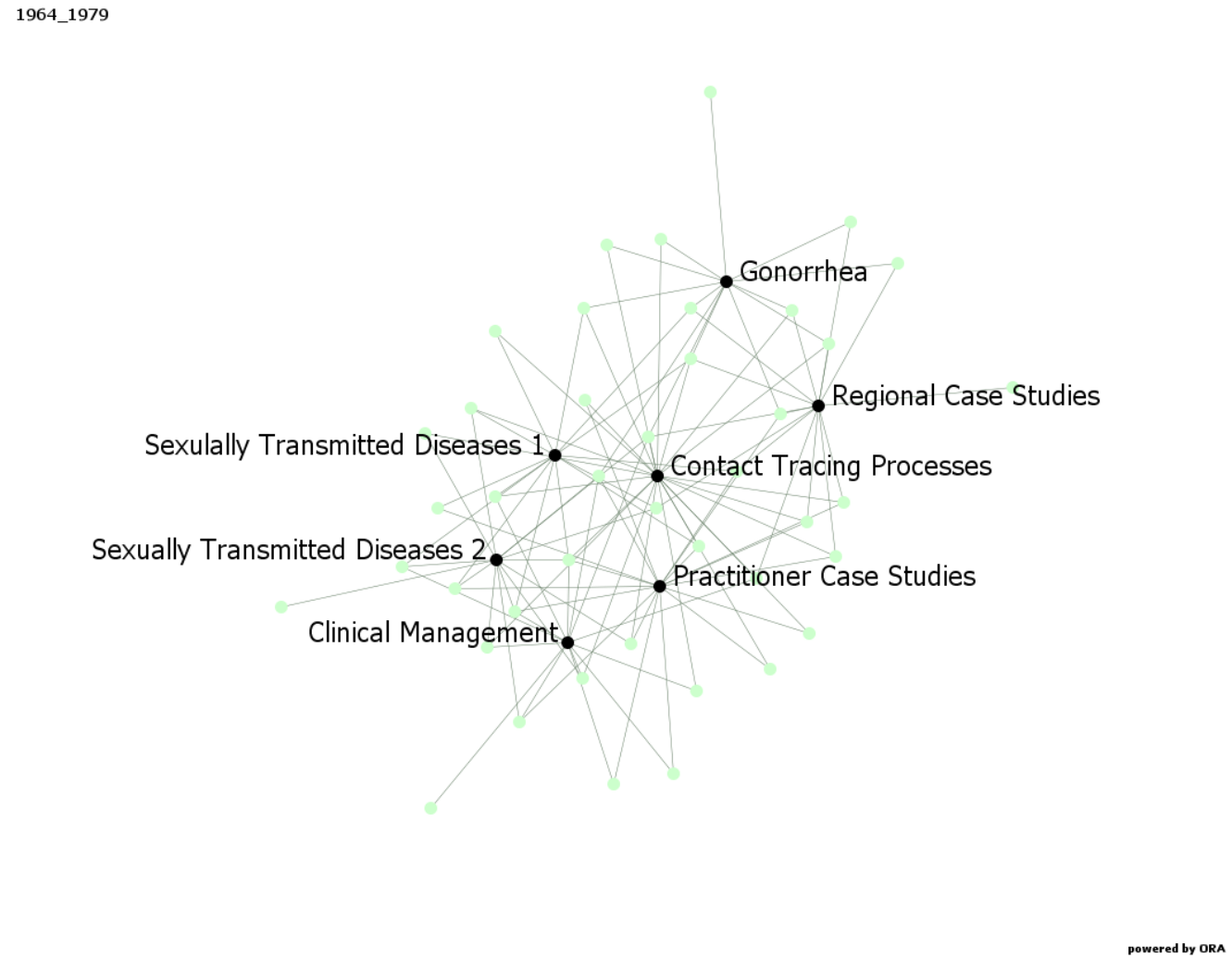


*Figure 4.4: Network Visualization of Articles from 1980 to 1989*

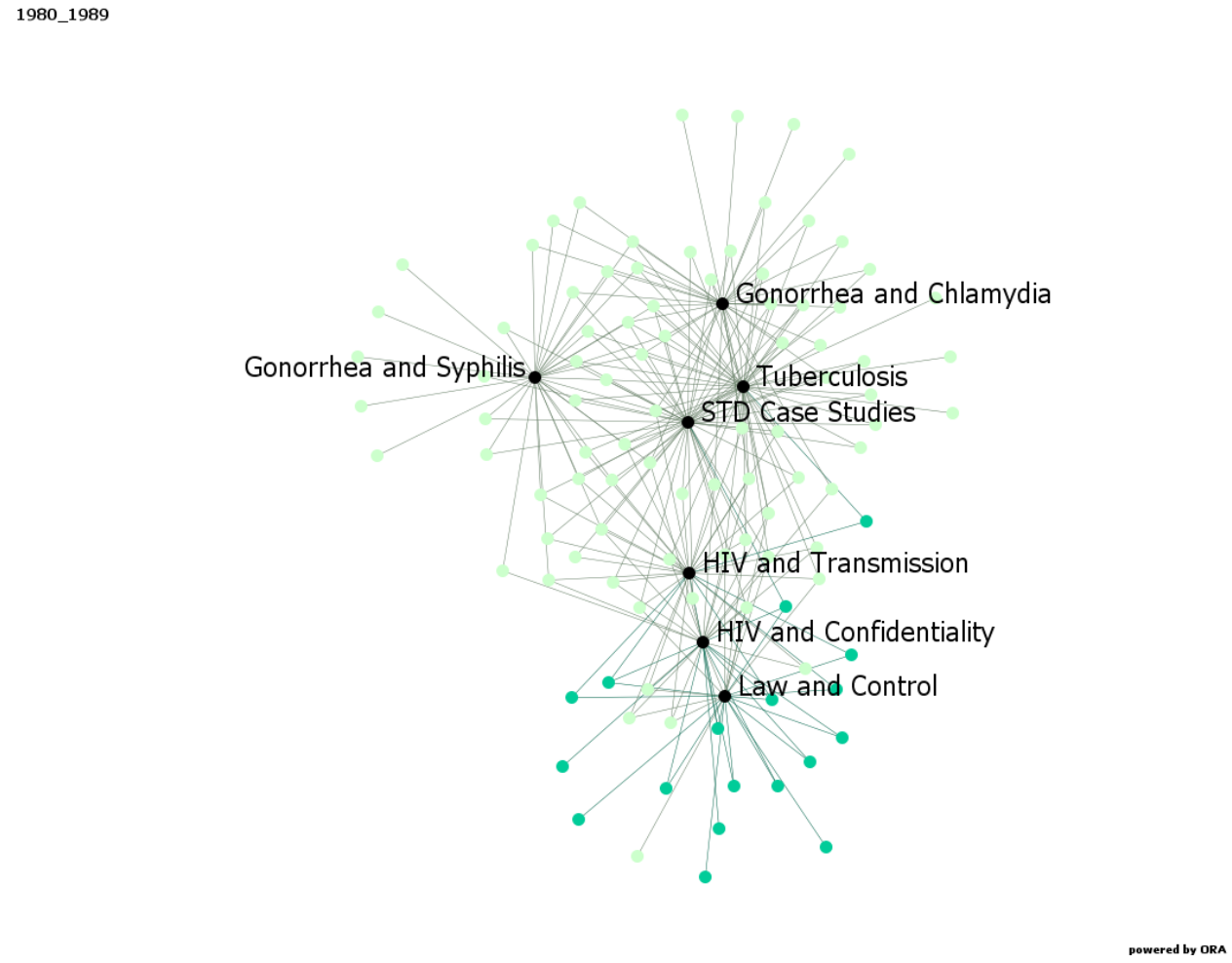


*Figure 4.5: Network Visualization of Articles from 1990 to 1999*

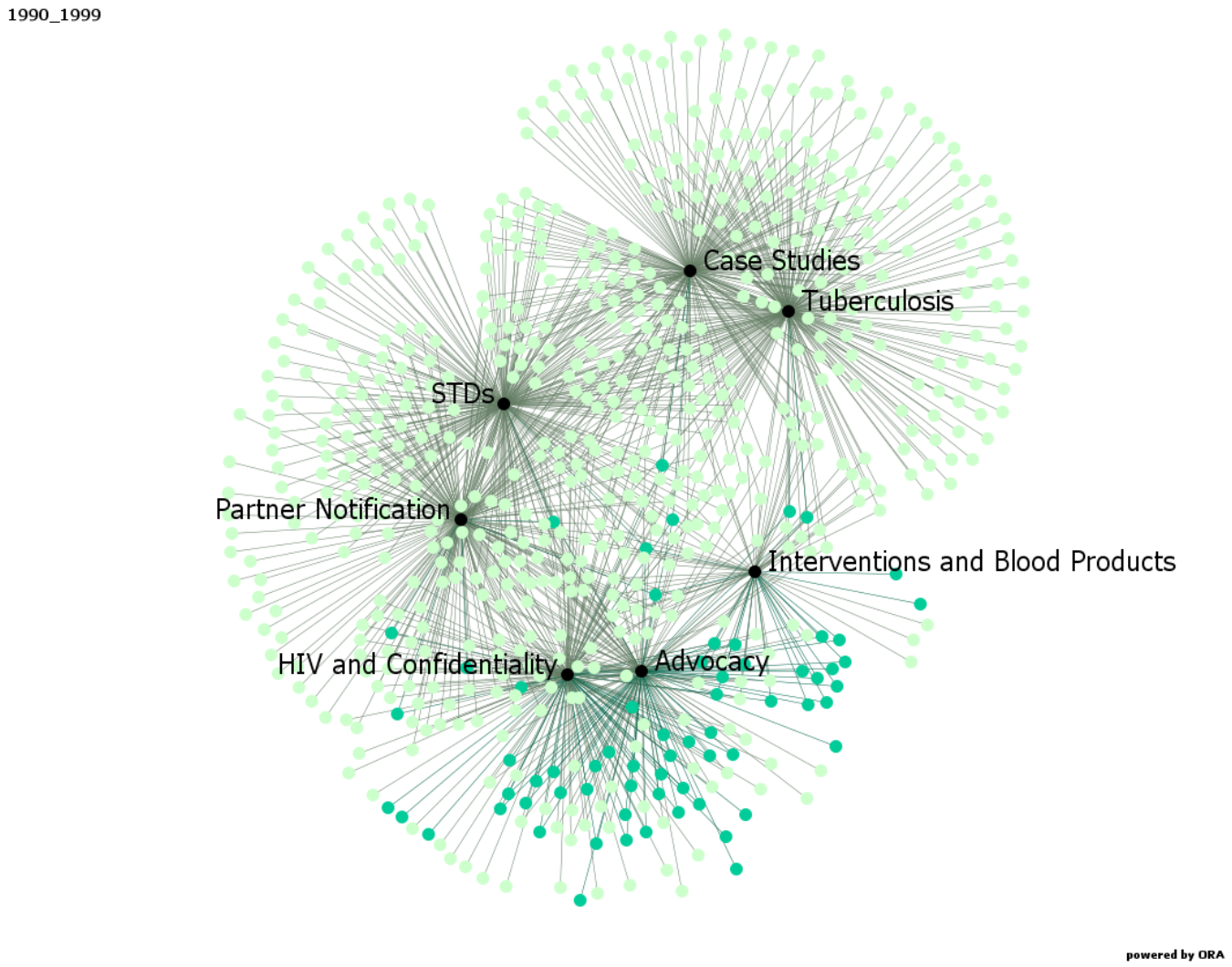


*Figure 4.6: Network Visualization of Articles from 2000 to 2009*

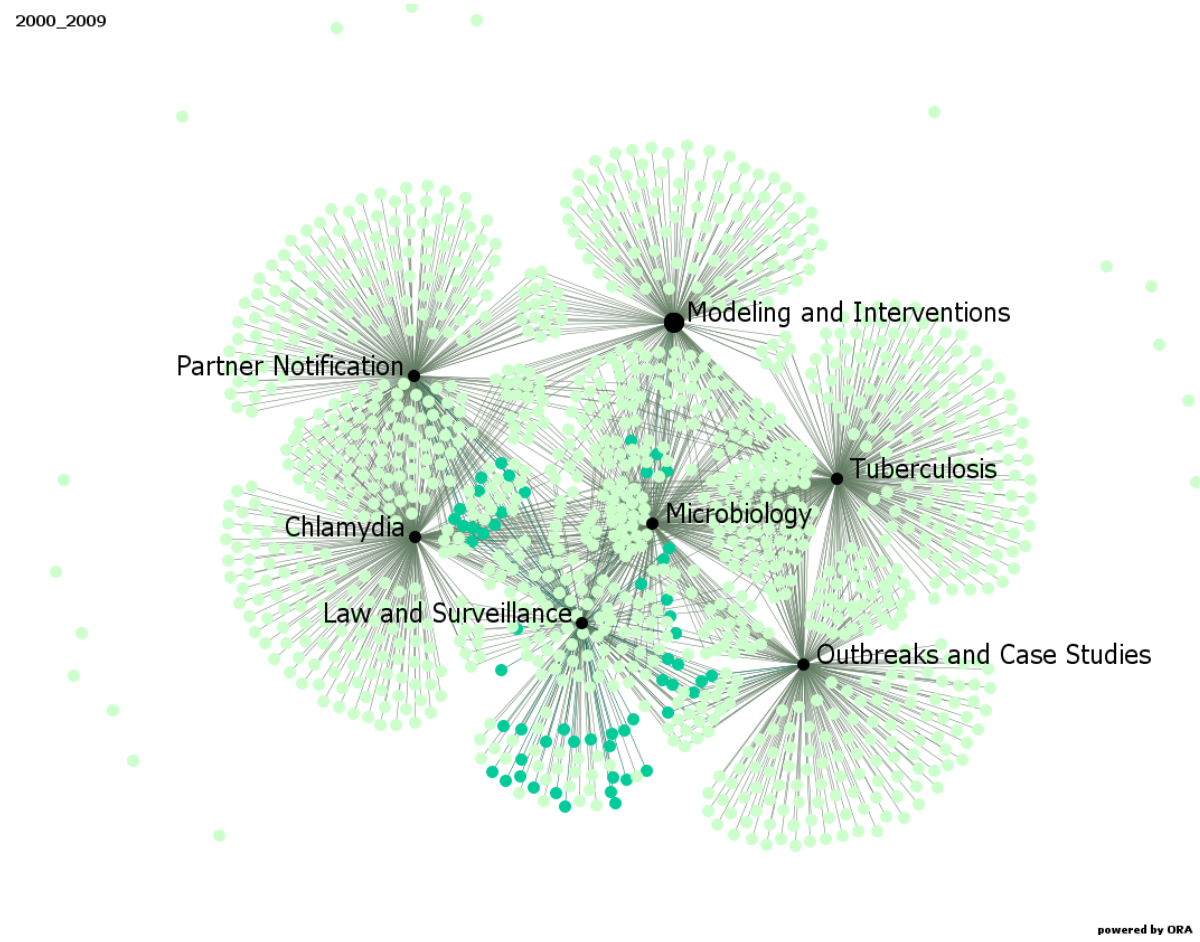


*Figure 4.7: Network Visualization of Articles from 2010 to 2019*

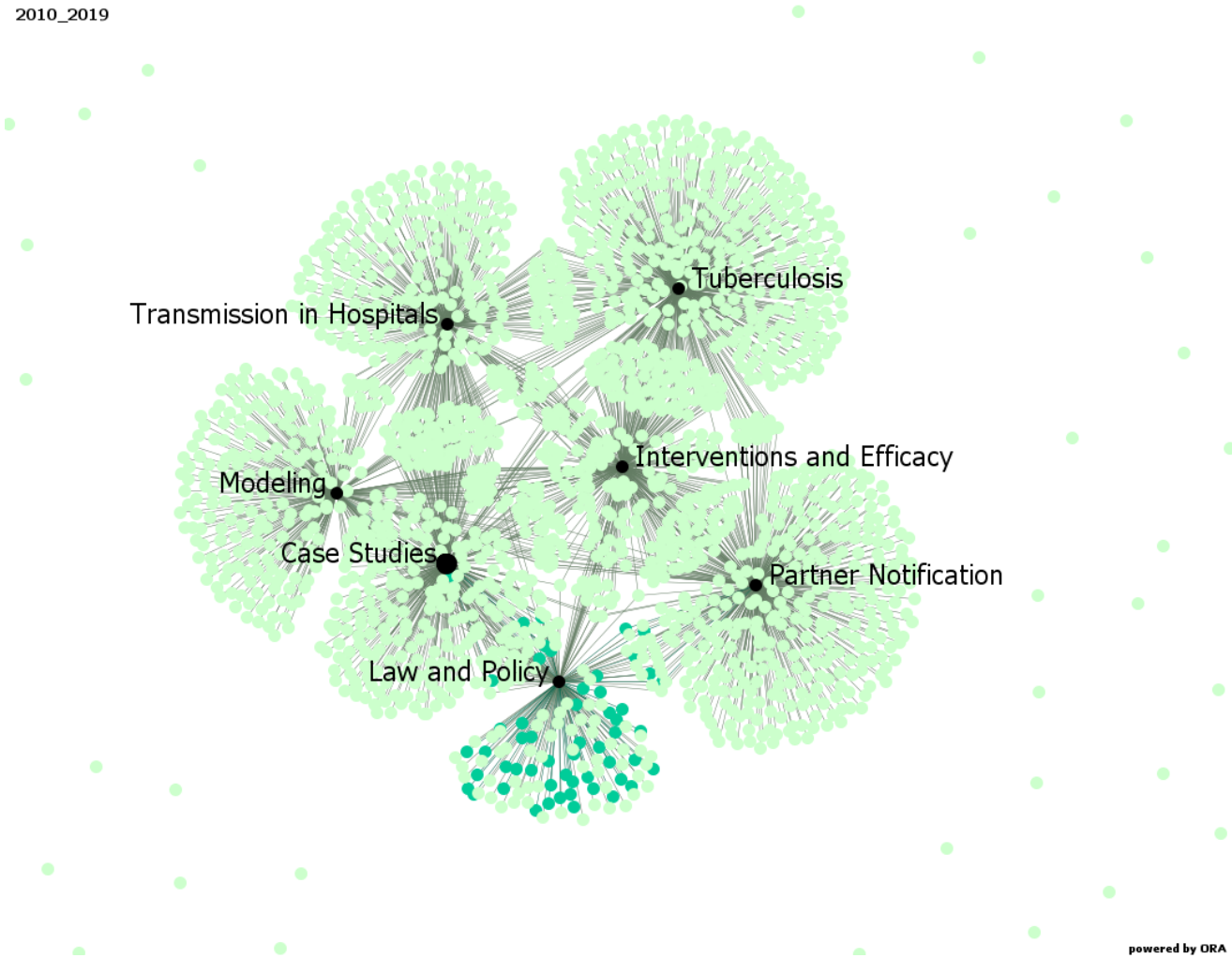
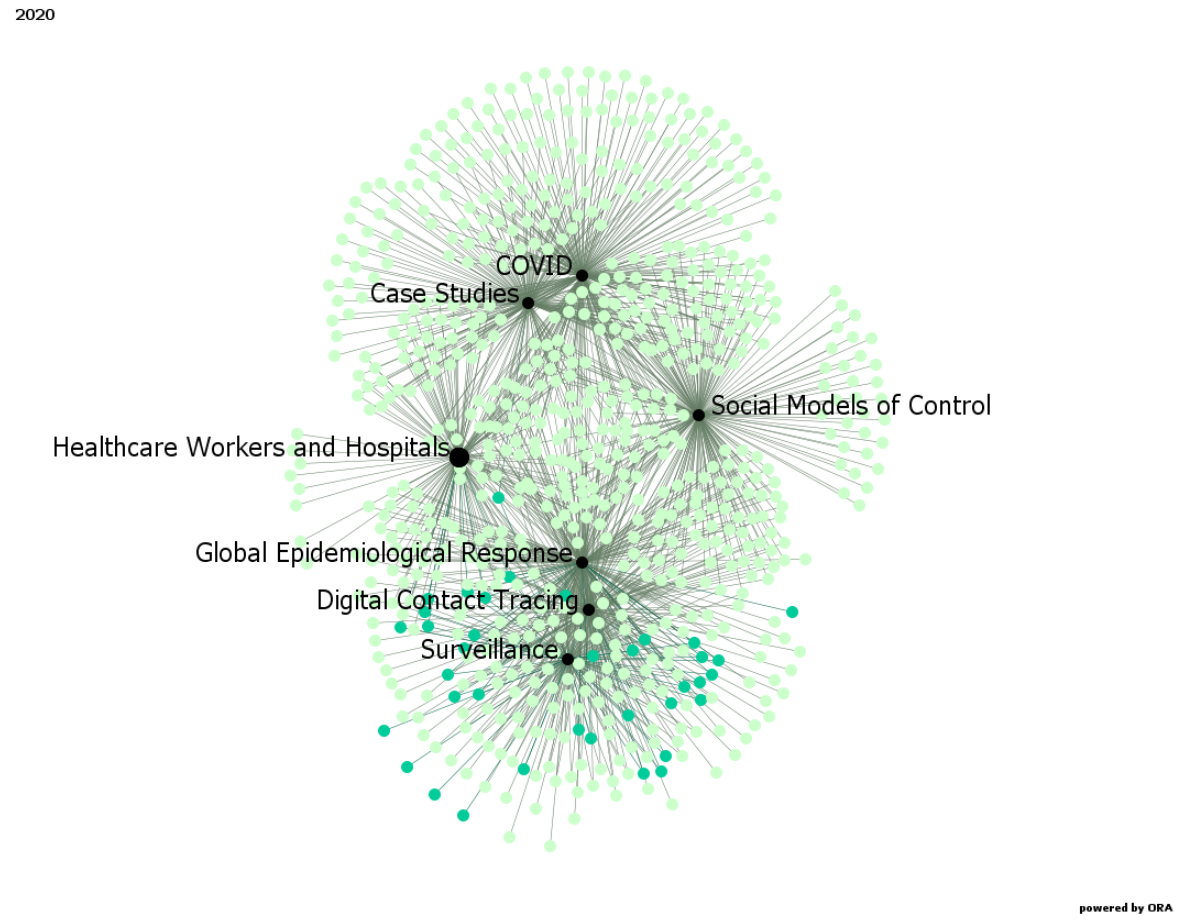


*Figure 4.8: Network Visualization of Articles from 2020*



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# CHAPTER 5

# OBSTACLES TO CASE INVESTIGATION AND CONTACT TRACING: PERSONAL, STRUCTURAL, AND IMPASSABLE BARRIERS TO ELICITING CLOSE CONTACTS FOR COVID-19 CASE INVESTIGATION, A QUALITATIVE STUDY*

*Target Journal: Journal of Public Health Management and Practice
Co-authors: Laura G. Meyer, Jasmine Truong, Megan Jehn, Julia Jackman, and Mick Salik.

**Abstract:**

*Background:*

Early in the COVID-19 pandemic contact tracing was touted as an essential public health tool that would allow for a return to normalcy. Two years later contact tracing has been largely unsuccessful in the United States. This research explores the experiences of on the ground contact tracers and the barriers they found to eliciting contacts.

*Methods:*

We conducted 14 interviews with active case investigators assess the attitudes and experiences of contact tracers working for the ASU Student Outbreak Response Team (ASU SORT) COVID-19 case investigation unit in Maricopa County, Arizona from July of 2020 to July of 2021. Interviews were transcribed and thematically coded using MaxQDA.

*Results:*

Case investigators interviewed for this research indicated that certain personal skills, such as active listening and remaining calm, confident, and rational while talking to cases had a positive impact on eliciting contacts. They also had specific questions and phrases they felt improved their contact elicitation. Case investigators also indicated that certain structural barriers prevented them from eliciting contacts, including

receiving cases weeks after the positive test and the need to follow scripted interview questions. Other intra-individual barriers included a general community distrust of public health. Uniquely, some case investigators also expressed that there were intra-individual barriers to contact tracing that were out of their hands – contact elicitation might depend entirely on luck of the case draw.

*Conclusions:*

The experienced case investigators interviewed for this research indicated several lessons learned where contact tracing successes can be replicated. Areas where case investigator-level interventions can affect outcomes include training case investigators in active listening, empathic communication, and coaching them on calm, rational, and confident speech. Areas where structural changes can affect outcomes include receiving cases expediently from testing providers and using the survey instrument to tee up prompts and or scripts that assist in contact elicitation such as asking for behaviors where cases might be in contact with other individuals. Unfortunately, case investigators also indicated that for a portion of cases, nothing can be done and only luck is involved in eliciting contacts.

## Introduction

In the first 24 months of the COVID-19 pandemic there were over 78 million cases and 934,000 deaths in the United States.[1] COVID-19 has taken over the public discourse and public health departments at various levels of government have spent two years struggling to combat the virus, as well as public backlash around masks, vaccines, and other public health interventions simultaneously.[2]

Back in March of 2020, with a highly contagious virus spreading rapidly through the community and no established treatment for COVID-19, government entities,

including public health departments, across the United States attempted to implement non-pharmaceutical interventions like social distancing orders,[3] free testing,[4] and mandatory interstate quarantine.[5] Many jurisdictions also quickly launched case investigation and contact tracing teams early in the pandemic to attempt to meet the unprecedented surge and mitigate the spread.[6,7,8] Prior to the availability of COVID-19 vaccines, contact tracing, notification, and targeted isolation was heralded has the less invasive alternative to blanket lockdowns.[9]

There has been a significant amount of research, both qualitative and quantitative, investigating the failures (and successes) of digital contact tracing, both in the United States and abroad.[10,11,12,13,14] The reality is that some of the "digital" contact tracing methods that were very successful in countries like South Korea are very unpalatable (or even illegal due to privacy laws) in the United States.[15] South Korea relied on a network of surveillance cameras, credit and debit card transactions, and phone logs in order to track individual movement and trace contacts.[16] Much of the research on contact tracing focuses on new, complicated technology that was never widely deployed,[17,18] instead of assessing why traditional contact tracing, which was successful abroad,[19,20] underperformed here in the United States.

Despite all of this early pandemic media attention about the potential of contact tracing, it has not clearly been successful in the United States.[21] A JAMA study analyzing data from June 1 to October 31, 2020 found that out of 74,185 lab confirmed COVID-19 cases across 13 health departments and 1 Indian Health Services Unit, only 1/3 of those were both reached by the health department and named at least one contact when interviewed.[22] Data from our own team, the ASU Student Outbreak Response Team (SORT), similarly shows just under 1/3 of our 24,507 interviewees have given close contacts.

Quantitatively measuring the success of contact tracing programs in the United States has proven difficult. A recent Coursera Johns Hopkins Massive Open Online Course targeted at public health practitioners offers a new tool for evaluation of local contact tracing programs (the Contact Tracing Evaluation and Strategic Support Application (ConTESSA)).[23] This tool offers opportunity for contact tracing programs to estimate their impact on community transmission of COVID-19 based on the number of cases detected in the community, the number of cases isolated, and number of cases who were identified during contact tracing. It also requires estimating the total number of infections in the community. While these metrics offer an opportunity to examine how a contact tracing program could lead to a reduced community transmission rate, it relies on quantitative parameters regarding isolation and quarantine behavior (and or assumptions about these parameters) that many health departments do not have available because they do not have systems in place to track these numbers.

In their recent JAMA Network Open paper that looks at the effectiveness of case investigations and contact tracing, Rainisch et al. had to model the potential effective isolation and quarantine compliance because the 23 jurisdictions in their study did not have that data.[24] After estimating that 80% of cases interviewed, 80% of monitored contacts, and 30% of notified contacts complied with isolation and quarantine guidance, they found that case investigation and contact tracing may have averted as many as 1.1 million cases and 27,231 hospitalizations. They estimated that that level of compliance may have reduced the overall COVID-19 burden by 17%. Importantly, they noted a difference in potential case reduction by region and found that the case investigation and contact tracing performed least successfully in the West. Rainisch et al. specifically call for further research that explores the characteristics of case investigation and contact

tracing in Western states to see if the differences are driven by public acceptance of case investigation and contact tracing or programmatic implementation factors.

Initial qualitative research on contact tracers working on COVID-19 has focused on the early pandemic. A study on the New Haven Health Department and Yale University joint team has looked qualitatively at barriers faced by volunteer contact tracers in the first three months of the COVID-19 pandemic.[25] They identified 12 themes through qualitative focus group analysis that they categorized and assessed based on the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) public health intervention evaluation framework. Their data show concern from investigators related to Reach in the form of difficultly establishing rapport with cases due to lack of trust and low public awareness. Their investigators also expressed challenges to Effectiveness through delays in the form of late reporting of test results to the team.

Another qualitative study in Ghana looked at both established (trained pre-COVID) contact tracers and COVID-19 contacts in the first two months of the pandemic.[26] The researchers in Ghana also found that their contact tracers expressed concern about delayed receipt of test results. They also expressed concern about mistrust towards public health from cases and contacts.

A recent qualitative study of six local health departments in the United States also assessed their experiences with contact tracing tools and rapid pandemic response. The health departments ranged in size from servicing populations of less than 50,000 people to over 500,000 people.[27] Clements and Baum found that all six local health departments expressed feeling overwhelmed, and 83% reported feeling frustrated with data collection. Clements and Baum also noted that there were concerns by local health departments about difficulty reaching cases due to being perceived as spam calls.

No research to date has looked at case investigators' experiences and contact elicitation outside of the initial phase of the pandemic in a United States jurisdiction as large as Maricopa County. This research explores the difficulties faced by case investigators and contact tracers working in the United States for an extended period of time during an active pandemic. Our aim is to better understand the challenges face by case investigators and contact tracers in order to better understand the role of case investigation and contact tracing in mitigating the impact of the pandemic.

**Background**

Maricopa County, the fourth most populous county in the United States with 4.4 million people, contains 62% of Arizona's total population.[28] Between January 2020 and December 2021, Maricopa County experienced over 818,000 COVID-19 cases and 13,000 deaths.[29] In March 2020, Arizona State University and their Student Outbreak Response Team (SORT) entered into a partnership with the Maricopa County Department of Public Health to conduct case investigations of individuals who had tested positive for COVID-19.[30] These case investigations included phone interviews with positive cases regarding their symptoms, demographics, and included questions to elicit close contacts of cases to pass on to Maricopa County and Arizona Department of Public Health for further contact tracing activities.[31] A close contact in survey was defined per the Centers for Disease Control guidelines at the time as a person with whom the case has been within 6 feet of for more than 15 minutes over a 24-hour period or a person with whom the case had had physical contact.[32]

**ASU Student Outbreak Response Team (SORT)**

ASU SORT has operated continuously since June 2017 and includes paid staff, student interns, and community volunteers. The team shifted to exclusively working on

COVID-19 in June 2020. At the time of this research in June of 2021, the ASU SORT had just under 100 active case investigators.

ASU SORT operates remotely, with case investigators reaching out to individuals who test positive for COVID-19 to conduct interviews via phone. Case investigators are trained over the course of 1-3 weeks using the Johns Hopkins Contact Tracing Course,[33] a standardized university HIPAA training module, several hours of asynchronous training specific to our team procedures and technology, and multiple live virtual sessions covering case investigation procedures, empathic communication, and role plays. Additional trainings, both asynchronous and live, have been added throughout the 20-month tenure of the team to address emerging needs and concerns, including additional empathy, HIPAA, and ethics training.

At the end of each shift, case investigators are asked to supply their shift supervisors with three specific data points for both quality control and data integrity: the number of calls made, the number of interviews completed, and the number of contacts elicited. These numbers are then logged and allow program managers to assure data quality and case investigator productivity. Benchmark goals for experienced volunteer case investigators are 4-5 calls an hour. For paid case investigators, the goal is over 6 calls an hour. The goal for all case investigators is at least one contact elicited per case investigation interview.

Between the start of the team's work on COVID-19 case investigations and the time qualitative interviews were conducted in May through June 2021, ASU SORT completed on average 429 interviews per week. During the same time period, an average of 69 interviews per week were unable to be conducted due to refusal by the case to participate. These data fluctuated with cases over time. *Figure 5.1* shows the number of

refusals to participate, interviews completed and overall cases closed weekly from July 2020 to June 2021.

## Methods

*Data Collection*

We conducted individual interviews with experienced workers on the ASU SORT case investigation line. We sought to uncover their experiences working on the line and illuminate their attitude towards eliciting contacts. Researchers used a purposive sample of interviewees from the pool of experienced members of the ASU SORT. We reviewed the interviews after they were conducted for content and themes. After 14 interviews were conducted and common themes were appearing in three or more interviews, we concluded soliciting interviewees.[34] [35] Interviewees were all over the age of 18 and had been working with the Team for at least three months. Some interviewees were volunteers with the team who received no compensation for their time on the case investigation line. Other interviewees were current or former members of an internship class where they received course credit for their hours on the line. Current internship students received the equivalent of .5 internship hours (out of a required 135) for their participation in an interview. Other interviewees were paid case investigators who received renumeration for their work. There was no financial compensation for the interview itself and participation did not affect volunteer status, pay, or course grade. Each participant completed only one interview. All interviews were conducted via Zoom. Prior to each interview the interviewee was sent a consent form approved by ASU's IRB to review and sign. The consent form was read at the beginning of each interview. Each interview was audio recorded with permission from the interviewees.[60]

[60] For more information about the specifics of our data collection and storage privacy procedures, please see the IRB Approval document in Appendix B.

Researchers used a semi-structured interview protocol that asked case investigators about their experiences conducting case investigations and contact tracing for the ASU SORT. The semi structured interview protocol covered why interviewers chose to join the team, what a typical call was like, how their experience was on the line, how they built rapport or a relationship with cases, how confident they felt in their ability to connect with cases, and how confident they felt with eliciting case close contacts. The protocol was piloted with two initial interviews and edits to the protocol were made. Neither of these pilot interviews are included in the research sample.

Interviews were collected by two researchers (LCW, the primary researcher and a female PhD candidate, as well as MS, a male MSW candidate) in April and May of 2021, after the case investigation team had been in operation for one year. Interviews were regularly reviewed by the team and continued until it was confirmed that thematic data saturation was achieved. Each interview took about 30 minutes. Interviews were automatically transcribed using the existing Zoom software and text file transcripts were hand cleaned by researchers. Text files were then loaded into MaxQDA.

This qualitative study was part of a larger project that sought to use qualitative data to assess the experiences and perceived efficacy of case investigators who had been working with the ASU SORT.

*Data Analysis*

Once in MaxQDA, researchers reviewed the entire corpus of interviews before meeting to discuss the themes. The primary researcher (LCW) inductively created a codebook focusing on contact elicitation specifically. The entire team discussed the codebook and reviewed examples. Both the primary researcher and the coder (JJ) independently coded the entire dataset. They then met to discuss and resolve any disagreements. Codes were not exclusive, and two codes could be present in one

statement. All interviews were coded and then checked for inter rater agreement. Additional edits to the codebook were made and the interviews were recoded. On the second coding pass, researchers reached an acceptable level of inter-rater agreement.[36]

**Results**

At the time of research participation, ASU SORT consisted of 20 regular volunteers, 62 students, and 10 paid investigators. *Table 5.1* includes the characteristics of the interviewees and the team overall. At the time of research, ASU SORT's paid CI staff was made up of majority undergraduate students, and so the average age of the interviewees is 26. Four of our interviewees were bilingual and conducted case investigations in Spanish. The average number of contacts elicited per interview for ASU SORT overall is less than 1 (.82). The case investigators interviewed for this study represent some of the team's most experienced and successful workers. Even in this experienced group, their average number of contacts elicited per call was .99.

*Identified Themes*

After initial review of the interview data, two codebooks were developed. One codebook focused on empathy and efficacy throughout the interviews. The second focused specifically on barriers faced by case investigators in response to the questions about eliciting contacts. Researchers identified 4 primary themes in related to the elicitation of contacts in the dataset: personal skills and effort, structural barriers, trust, and impassible barriers.

*Personal Skills and Effort Theme*

Case investigators described specific skills or efforts that they employed to increase their chances of successfully eliciting contacts from cases. This theme focused specifically on individual behaviors case investigators attempted to elicit contacts. Some of these skills included specific phrases they used:

> I found it's really helpful to say “are there any concerns that you have?”.... leaving that open ended question for them to tell me if it’s security concerns or if it's that they already informed all their contacts (Participant 004, Pos. 155)

Some interviewees mentioned general conversation strategies, such as asking cases to name the other individuals in their household. Others skills applied more generally, such as behaving confidently, calmly, and rationally:

> Other skills would include being calm, being rational, because sometimes, during a call, a case may ramble on or they may start talking to [you] with an attitude, in a rude kind of way. (Participant 006, Pos. 122)

Another area discussed was around modifying and modulating tone through the canned script to build rapport. These modifications included suggestions to avoid the rigid nature of the script, for example: “I don't try to sound like a robot” (Participant 009, Pos. 89).

Having a common language was also considered part of rapport building by one case investigator:

> I elicited the most contacts out of our team, mainly through [my calls with] the Spanish-speaking [cases]. Having that solid connection with them throughout the interview really helps [me] to get them to be comfortable to elicit those contacts. (Participant 011 Cleaned, Pos. 92)

Listening was also mentioned as essential to getting cooperation in terms of both leading the case investigator to ask the right questions and building trust:

> First, I'll listen to them --walk [them] through what happened, “you know you got sick on Friday. Let's go back two days before --that was the Thursday or Wednesday before. Now, since then, who have you had a close contact with?” (Participant 009, Pos. 88)

> [I] encourage people to participate through my listening skills and encourage them to share their experience with us. When I get to the contact tracing portion typically I already have quite a lot of information, which helps me to ask the right questions, that I know are relevant, that might help lead me to that contact elicitation. (Participant 012, Pos. 91)

*Structural Barriers Theme*

Case investigators also described structural issues with how case investigations or public health efforts were conducted that affected their ability to elicit contacts. These structural barriers were specific things over which the case investigator had no control. Structural barriers might be difficult problems, but are ultimately theoretically solvable, specific issues.

A common structural barrier was the timing of when we received cases. Over the course of the pandemic, Arizona and Maricopa County experienced various waves in cases that would in turn lead to extremely high volume of calls to be completed. Due to issues with testing infrastructure, data transmission from labs to the health departments, and then further sorting of cases to teams for case investigation, at various points during the pandemic ASU SORT would receive cases late in the incubation period when quarantine and isolation is less effective for slowing transmission. Case investigators expressed that these delays in receiving the cases for investigation caused multiple problems:

> I feel more confident the earlier we elicit contacts. Sometimes if we're trying to elicit contact when they tested positive 11 or 12 days ago, they are a lot less likely to give those contacts because they're saying like "Oh, they would have already gotten COVID by now" or "I'm already over in my own isolation, why would I

> need to give contacts right now, if I'm done with COVID" (Participant 002, Pos. 170)

> Sometimes they simply forget because their contacts were from a long time ago, and so they don't remember who they came into contact in the time that they have COVID. (Participant 006, Pos. 114)

Other structural issues included changes to the survey instrument used by the case investigation team. One case investigator noted the specific utility of the question that asked how many people were in a case's household:

> I'm happy that the question about how many other people in your household was added to the survey pretty recently, because I think that really establishes a good base level for contact tracing because then I can just ask, can you name those other people in your household. It's really more natural than what was happening before. (Participant 007, Pos. 140)

*Trust Theme*

Case investigators also occasionally described the lack of trust as a specific barrier to eliciting contacts. Case investigator statements coded under this theme included descriptions of cases not trusting government or other institutions with their information:

> I think that sometimes the cases don't trust what the county is doing, and so, because of that, they don't want to really give our contact information and phone number. I have experienced some calls where you know they know their contacts, but they don't want to provide their phone numbers to me because they don't trust [us]. (Participant 006, Pos. 113)

This themes also included more general concerns case investigators had seen expressed by cases about where their information was going:

> One of the things that really helped me with the Spanish-speaking cases was being able to establish that connection. That kind of helped me build confidence with them and assure them that we're not using this information for any evil practices or anything of that sort. (Participant 011, Pos. 91)

> I feel like people think we're trying to get more information out and trying to get their contacts for some subscription service or something (Participant 004, Pos. 145)

*Impassible Barriers Theme*

One of the most surprising themes described by case investigators in the interviews was the "impassible barriers" theme. This theme covers case investigators describing situations or indicating that there is nothing they can do to elicit a contact in a given situation. This theme was distinct from the themes around personal effort, structural barriers, and trust because here there was no clear or proximate reason for the case investigator to be having difficulty eliciting contact from the case. This theme was present where case investigators expressed hopelessness or the "coin flip" nature of making case investigation calls:

> A big part that played into me not being as confident was not seeing any change, despite changing our way of communicating that question to them. I think that's the root of my lack of confidence. People just seem in general, not willing to share information like that. (Participant 001, Pos. 66)

> I [try] to push and it's just the same for every single case, sometimes it works, sometimes it doesn't. (Participant 003, Pos. 136)

> I think it depends on a lot of different factors. Like luck. Sometimes somebody [is] fatigued with the call and just wants to be done with [the call] (Participant 005, Pos. 121)

**Discussion**

This research aims to document and illuminate practitioners' experiences in a specific area of public health practice: contact tracing. This research shows that for eliciting contacts, case investigators found certain barriers including personal efforts, structural barriers, trust issues, and impassible barriers. While many developed individual skills and approaches that helped in eliciting contacts, case investigators also found barriers outside of their control in the form of structural issues, case trust, and other factors

Much public health capacity and implementation research aims to assess the appropriateness and effectiveness of interventions including case investigation and contact tracing.[37] Since many COVID-19 case investigation and contact tracing teams in the United States were built or expanded on the fly while the pandemic was ongoing, the amount of research assessing their effectiveness has been limited. By March 2021, CDC had distributed over $42 billion to state, territorial, and local health departments through the Epidemiology and Laboratory Capacity for Prevention and Control of Emerging Infectious Diseases (ELC) program.[38] Over $851 million of that went to Arizona. With that amount of money going to public health activities, including case investigation and contact tracing, it is crucial to have multiple assessments of programs, including qualitative. This research provides key insight into the challenges of contact

tracing in the United States. Understanding the experiences of contact tracers on the ground is essential for informing public health decision-makers and determining whether to sustain and or redesign these programs.

Most encouraging, there do appear to be specific skills that case investigators mention that assist them in eliciting contacts. Specific phrases that case investigators find effective can be quickly shared within a team and added to case investigators repertoire of off-script remarks. Other empathic communication skills, like active listening can be trained and practiced as well. ASU SORT employs an empathic communication guide developed by one of our principles through work on case investigation that offers training on naming emotions, validating them, respecting cases, offering support, and exploring further communication.[39] General strategies, like speaking calmly can also be taught to case investigators. Finally, the experiences of our Spanish-speaking case investigators suggest that it is important to have case investigators who are linguistically and culturally aligned with the case population as well.

The most common structural issues mentioned by case investigators are theoretically simple to correct. Cases arriving in the queue 7 to even 14 days after obtaining a positive test makes it difficult to conduct useful contact elicitation when the case is already out of isolation themselves. Public health departments should strive to get case contact information to investigation teams expediently, however, in surges where there are testing and reporting backlogs, this can prove difficult, and per other Clements and Baum may require additional technology tools and data infrastructure that have implementation lags and learning curves[40].

Case investigators also mentioned that changes to the survey can also aid in contact elicitation. In particular, a question about how many people were are in a case's

household provides a clear jumping off point for eliciting close contacts. At various points during ASU SORT's operations other questions have been discussed in relation to the case investigation survey instrument, including questions about whether cases have been to any restaurants or large events. Unfortunately, because of testing and validation, as well as bureaucracy, survey instruments that are widely deployed can be difficult or slow to change.

Unfortunately, case investigators also expressed that there are sometimes impassible barriers or nothing they can do to elicit contacts. Case investigators indicated that sometimes it was "luck" and the particular case they were tasked with speaking to was willing or unwilling to offer contacts and nothing could be done to change the outcome. One case investigator in particular expressed frustration at how their own behavior and training seemed to do nothing to change the outcome with respect to eliciting contacts. This defeated attitude reflects the low levels of contact elicitation across the team. The average number of contacts eliciting from a case investigator interview is less than one per call. Contact elicitation is extremely difficult and many case investigators experience frustration in response to repeated inability to elicit contacts. This frustration can lead to public health workforce burnout, which is important to address

This impassible barriers finding is important. While much public health efficacy research focused on strategies to improve reach and effectiveness, it is crucial to acknowledge that not every intervention will be successful and that individuals tasked with completing this intervention may feel frustration or even burn out at attempting to reach a population or conduct public health practice amongst a hostile audience. Allowing space for individual feelings, and larger failures is essential to continued interventions.

**Strengths and Limitations**

This research provides a unique look at a team and case investigators who had been practicing for an extended time, on a high case volume team, in the 4th most populous county in the United States. ASU SORT has operated continuously, through multiple waves of the COVID-19 pandemic and thus case investigators interviewed worked an average of 10 hours a week, during the pandemic for an average of 6 months (with the shortest period of time with the team at over 3 months, and the longest at over 10 months).

While this research population was very experienced in case investigation, because of the nature of the ASU SORT team, the case investigators were young and had limited public health workforce experience, with an average age of 26 and 9 of the 14 interviewees being under the age of 22 and the majority, 11 out of 14, were or had been recent undergraduates at Arizona State University.

Qualitative studies are limited in their utility for generalization. This research occurred in a very specific context. Interviewees were working in a county and state that has been criticized for its COVID response in terms of rushed re-openings,[41] attempted mask bans,[42] and the banning of vaccine mandates.[43] Perception of the pandemic and COVID-19 contact tracing will be different in other parts of the country and world that have a different relationship between the population and public health. This research also took place at a very specific time. It occurred one year into the pandemic, when vaccines were starting to become widely available in the United States and before the Delta variant became the dominant COVID-19 variant in June of 2021.[44]

This research also only addresses the experiences of case investigators and their perceptions. Actual discussion with cases, their experiences of the calls, and their reasoning for refusal to give contacts would provide additional insight.

## Conclusion

This research points towards several areas where contact tracing teams can focus efforts to improve contact tracing. Training case investigators on confidence, as well as active listening are key skills in eliciting contacts. This research also points to ensuring the contact tracers share key characteristics with the case population, including language. This research also shows the need to train case investigators in resilience, as sometimes there is nothing that can be done to elicit contacts.

## Author Contributions:

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**Tables and Figures:**

*Figure 5.1: Refusals to Participate, Interviews Completed and Overall Cases Closed from July 2020 to June 2021*

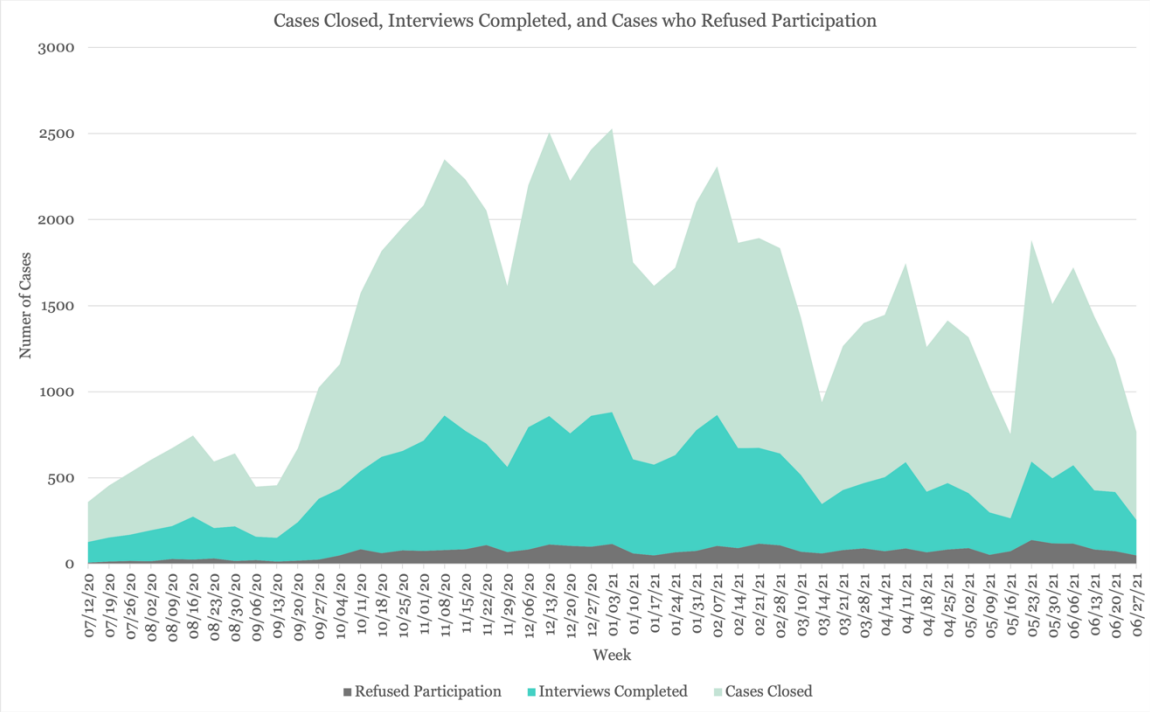


*Table 5.1: Case Investigator Participant Characteristics*

| **Characteristics** | **Interviewees** (n = 14) |
|---|---|
| Age, median years | 26 |
| *Gender* | |
| Male | 5 |
| Female | 9 |
| Spanish-speaking | 4 |
| *University Affiliation* | |
| ASU Undergraduate Student | 11 |
| *Team Status* | |
| Paid Case Investigator | 10 |
| Volunteer | 3 |
| Course Student | 1 |
| Average Number of Contacts Elicited per Call | .99 |

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# CHAPTER 6

# ETHICAL ISSUES AND LEGAL EPIDEMIOLOGY IN COVID-19 CASE INVESTIGATION AND CONTACT TRACING: A CASE STUDY OF A LARGE ACADEMIC PUBLIC HEALTH PARTNERSHIP

*This chapter is in preparation for submission to the Journal of Law, Medicine, and Ethics, in collaboration with Laura G. Meyer and Megan Jehn.

**Abstract**

In an effort to respond to the large surge in COVID-19 cases in Arizona from May to July 2020, the Arizona State University (ASU) Student Outbreak Response Team (SORT) formed a remote, volunteer-based case investigation team working in partnership with a local public health department through delegated public health authority. The SORT contacts and interviews individuals who have tested positive for COVID-19 in Maricopa County to gather information on demographics, symptoms, and close contacts. The SORT consists of, at our peak, 225 active volunteers, interns, and staff, with differing academic backgrounds and professional expertise from undergraduate students to retired health professionals located locally and throughout the U.S. This paper provides a critical analysis of the ethical and legal issues the team encountered throughout training and public health practice. This paper underscores the importance of not only legal compliance but broader ethical and equity considerations in implementing a case investigation and contact tracing program that can respond effectively to an active pandemic.

**Keywords:** COVID-19 | contact tracing | ethics | law | legal epidemiology

## Introduction

Between March of 2020 and December 2021, Maricopa County, Arizona, the fourth most populous county in the United States,[1] experienced over 865,000 cases of COVID-19.[2] At various points during 2020 and 2021, Maricopa County and Arizona were considered global hotspots and had the highest per capita COVID-19 infection rates in the United States.[3] The overwhelming surge combined with limited public health staffing led to an expanded partnership between Arizona State University's (ASU) Student Outbreak Response Team (SORT) and Maricopa County Department of Public health. This large, remote, scalable case investigation response team was tasked with conducting case investigations of individuals who had tested positive for COVID-19 in order to provide community support and begin the process of contact tracing.[4]

Since the beginning of the COVID-19 pandemic contract tracing has been promoted as a key public health intervention by the Association of State and Territorial Health Officials (ASTHO),[5] the National Association of County and City Health Officials (NACCHO),[6] and the Centers for Disease Control (CDC)[7]. Contact tracing involves contacting or monitoring people with a suspected or confirmed illness and working with them to recall anyone who they were in close contact with during the time when they may have been infectious. The actual process and methods of coordinating contact tracing differ from jurisdiction to jurisdiction. In the United States, most jurisdictions opted to use manual contact tracing, in which contact tracers reach out to each positive or potentially positive COVID-19 case directly and interview them. Some jurisdictions incorporated digital tracking methods using phone Bluetooth or even other wearable devices. Interviews with confirmed positive cases are called "case investigations" and they are the first step in identifying close contacts for exposure notification. These interviews can also go beyond notification for the purposes of severing transmission

chains. Many case investigation and contact tracing teams also provide education to cases, share social support resources, and even can refer them to other governmental or non-governmental organizations that have useful resources for their particular situation.

SORT created a large, remote case investigation team that could reach out by phone to individuals who tested positive for COVID-19. SORT case investigators obtain demographic information, medical history, symptoms, employment status and history, travel history, and vaccination status of cases. Remote case investigation was necessary given the rapid increase in COVID-19 cases and the need for a large, sudden increase in case investigators. Despite specific delegated executive and public health authority to conduct case investigations and contact tracing,[8] the ASU SORT still had to navigate challenging legal and ethical issues associated with confidentiality, mandatory reporting, and the scope of case investigations.

In the past year, several case studies have been published on how public health departments[9] [10] have approached the process of manual contact tracing during the COVID-19 pandemic. Most cursorily address the need for compliance with HIPAA in public health practice and data collection during an emergent pandemic[11]. Few, however, focus on the legal and ethical challenges that arise when conducting this delicate public health process remotely, and the need to give more attention to legal training and practice to teams of nonlawyers. This paper describes 1) the legal hurdles and ethical challenges encountered by the ASU SORT, as well as solutions SORT employed to continue safe and secure operations in the face of unpredictable waves of cases and legal epidemiology, 2) the potential for legal case studies in public health law, and 3) the legal environment around COVID-19 in Arizona. Over the course of conducting case investigations the legal and ethical issues encountered by ASU SORT fell into three primary categories: (1) issues related to the confidentiality and privacy of cases

protected health information and other confidential data, (2) mandatory reporting requirements of case investigators and supervisors to address issues such as child abuse, elder abuse and medical emergencies, and (3) issues regarding the scope of work that should be performed by case investigators.

**Arizona and the Legal Landscape Around COVID-19**

Arizona has had a complicated relationship with public health during the COVID-19 pandemic. In addition to being a regional, national, and even global hotspot for COVID-19,[12] [13] both the governor and state legislature have at various points actively curtailed public health authority and limited public health response in the state.

The Arizona Governor first declared a public health emergency in response to COVID-19 on March 11th, 2020.[14] A week later on March 23rd, 2020 another executive order added COVID-19 to the state's list of mandatory report diseases and legally enhanced the ability for state and local health departments to surveil cases.[15] This and subsequent executive orders [16] [17] [18] [19] [20] [21] [22] require all labs to report the results of all COVID-19 tests, as well as the information about the case including their name, address, telephone number, date of birth, and gender, to the Arizona Department of Health Services. Most recently on October 7th, 2021, the governor extended this enhanced surveillance authority for the ninth time.[23]

Despite continuing to extend the surveillance capabilities of state and local jurisdictions to track COVID-19, the governor has resisted direct public health interventions such as mask requirements that attempt to respond to the data collected from public health contact tracing. On June 15th, 2021, the governor issued an executive order preventing the Arizona Board of Regents and institutions of higher education in the state from requiring vaccination for students, and requiring masks or COVID-19 testing.[24] Later that month, on June 30th, 2021, the state legislature passed HB 2898

which prohibited secondary schools from requiring students or staff to wear masks.[25] In September, an Arizona Superior Court judge found the anti-mask law unconstitutional under the state constitution Article IV pt. 2 § 13 because it was improperly included in a budget reconciliation bill.[26]

Amidst a tenuous political climate around public health, the ASU SORT has continued to collect data from cases. In addition to navigating the constantly changing, extremely politicized fluctuations in public health authority throughout the pandemic, the ASU SORT team has also had to ensure it complies with federal Health Insurance Portability and Accountability Act (HIPAA) data privacy requirements[27] and expansive mandatory reporting statutes that cover children,[28] vulnerable adults, and elders.[29]

**ASU Student Outbreak Response Team (SORT)**

In order to assist the Maricopa County Department of Public Health and meet case investigation surge needs, ASU SORT recruited volunteers from a variety of backgrounds. Undergraduate students who represent a range of disciplines from biology to engineering to social work joined the team, as well as community members who had backgrounds including everything from dog trainers to retired nurses. These diverse disciplinary backgrounds led to a wide range of baseline understandings about privacy concerns, HIPAA, public health, and ethics.

Between July 2020 and October 2021, ASU SORT trained over 450 case investigators. Investigators work remotely to call positive cases and collect surveys on their demographic information, symptoms, travel history, vaccination status, and close contacts. From June 2020 to October 2021, SORT case investigators have completed over 31,722 case interviews and elicited 24,884 close contacts.

From its formation, the SORT has taken extensive efforts to ensure the team operates in a manner that is not only legally compliant, but in a way that allows for equitable community impact and ethical engagement with cases.

## Legal and Ethical Lessons Learned

The American medical system is known for presaging autonomy and individual decision-making over other ethical principles like beneficence, non-maleficence, and justice. However, during an emergency, including a public health emergency, the autonomy of the individual takes a backseat to the needs of the community. This shift in focus to community needs from individual autonomy and decision-making can be a difficult transition for both public health practitioners and cases in the United States because most individuals are used to viewing the world, and especially things that are healthcare and healthcare adjacent through a lens of individualism and autonomy.

The three primary areas of legal and ethical issues are described in the sections following: (1) confidentiality and privacy; (2) mandatory reporting; and (3) scope of work.

### *Confidentiality and Privacy*

Generally, the American health system and public health system heavily weigh the autonomy of individuals. This includes treating individual privacy and confidentiality as paramount. However, during an active pandemic, the benefit of slowing the spread of a contagious illness begins to outweigh individual autonomy. In Arizona, the governors' COVID-19 surveillance executive orders enable the health department to collect and assess data on COVID-19 cases in the aggregate and individually.

Case investigations and contact tracing involve handling both protected health information and other sensitive, confidential information. Case investigators have access to names, birthdates, addresses, phone numbers, and COVID-19 positive status

before an investigation even begins. As a case investigation interview progresses, case investigators may learn additional information about a person's medical history, social history, current symptoms, and other personal information, such as their ethnicity, employment history, family, and social calendar. Ensuring that this health information is narrowly and properly disclosed is essential to case investigations.

ASU SORT uses an entirely remote workforce who communicates internally and with cases via a variety of technological platforms, including Microsoft Teams, Zoom, and Cisco Jabber/Amazon Connect. Case investigators work from around the United States to manually elicit contacts and other information from cases in Maricopa County. The remote workforce requires a different approach to monitoring and ensuring the security of each individual case investigators' work environment given that each case investigator is not physically present in a secure workspace using a controlled computer.

ASU SORT required all case investigators to sign a confidentiality agreement with both Maricopa County and the SORT team itself. SORT also provided specific training about best practices for confidential remote case investigation work, including steps to create a secure internet connection, the use of headphones, the requirement that cohabitants of the workspace not be within earshot, and the destroying of all written or typed notes outside the case file. Case investigators were required to appear visually via Zoom to confirm they were in a compliant environment prior to beginning a case investigation shift.

A second issue impacting confidentiality and privacy that arose early on was the use of proxies to conduct interviews for those who were unable to communicate via phone due to language barriers, physical or mental disability, or age. Given the population of Maricopa County, ASU SORT has a significant portion of cases occurring

in those who are minors, elderly, or who do not speak English proficiently enough to conduct an interview via phone.

Here the risk of information disclosure is that a person other than the COVID-19 positive case may learn of the diagnosis without the case's explicit consent. The benefit to public health is the collection of the case's interview. An additional benefit to the public included reaching and providing resources to otherwise underserved populations. With the rapidly increasing number of positive cases, especially among the elderly and Hispanic populations in Maricopa County, the benefit of gaining key information relative to the tracking and tracing of the virus, as well as providing cases with informational resources, can be considered as outweighing the risks to the individual.

ASU SORT, in consultation with ethicists at a local hospital system, developed a policy for conducting case investigation interviews via proxy that would allow for continued case investigations of these significant populations. Case interviews were conducted via proxy if at least one of two conditions was met: 1) the case provided explicit consent to be interviewed via proxy; or 2) the case lacks the capacity to complete the interview themselves due to minor status, illness, or other disability, and the proxy was able to confirm key identifying information about the case such as birthdate or address. Without the ability to use proxies, a significant portion of cases would not have been included in data collection, severely limiting our understanding of the spread of COVID in these populations. Moreover, these cases would not have received access to resources like COVID-19 isolation and quarantine guidance, letters of excused absence for employers, or direction to additional COVID-19 resources such as rental assistance, mutual aid, and migrant assistance, among others. Again, given the high number of non-English speaking cases in Maricopa County, this particularly vulnerable population would have been left out without the provisions for proxy interviewing.

*Mandatory Reporting*

Given ASU SORT's significant call volume to elderly and minor cases, the team became increasingly concerned about requirements of case investigators to report findings to other entities in the state of Arizona, either ethically or by law. Especially early on during the pandemic, concerns arose that the combined stressors of the pandemic would lead to increased violence against vulnerable populations[30] while simultaneously quarantine policies and school closures would limit interaction with external entities, like schools, where reporting most commonly occurs.[31] Given these concerns, SORT was acutely aware that our interactions with cases and their families put us in a unique position to potentially learn of issues with elder abuse and child abuse that were otherwise unseen. Additionally, in an ad hoc survey of 84 case investigators in November of 2020, 48% reported experiencing a difficult call they did not feel prepared to handle.

Under Arizona statute[32] medical professionals, social workers, peace officers, clergy, school personnel, and domestic violence victim's advocates who "reasonably believe" that a minor has been subjected to abuse are required to report to a peace officer, department of child safety, or tribal authorities. The elder abuse statue[33] requires treating medical professionals, social workers, attorneys, accountants, and conservators to report any abuse, financial or physical, to a peace officer or protective services worker. In the context of case investigators conducting public health practice, there is not a clear legal duty to report either child or elder abuse. However, an ethical duty existed given the unique social isolation of the pandemic and the unique access of case investigators.

ASU SORT developed a policy for reporting suspected cases of elder and child abuse that case investigators encountered. Line supervisors debriefed with case investigators after shifts and paid special attention to difficult call encounters. If a

situation brought up concerns of abuse, line supervisors enlisted support of program management to determine if next steps or reporting were needed. Case investigators were provided with support to decompress after difficult calls, and were often asked to support reporting processes. Collaborative decisions were made to determine who would make the report to the appropriate entity, line supervisors (many of whom were in active social work or healthcare delivery degree programs), or program managers.

For example, while completing a case interview a case investigator learned of drug use in the home of a minor case. Concerned with the child's well-being, the case investigator consulted with the line supervisor and ultimately with a member of the management team (who is also a social worker) to review the details of the call. As there was reasonable belief that the minor was exposed to illicit drug use, the program manager reported the concerns to appropriate authorities.

ASU SORT also encountered a similar issue with medical emergencies. At various points in the pandemic, case investigators were communicating with cases who were extremely ill and in urgent need of medical care. While there is no legal duty to report medical emergencies, there is an ethical duty. SORT worked with partners and created procedures for responding to cases who were in active medical distress. These procedures included asking to speak with other individuals in the home who could help (if available), linking the case with appropriate state medical support hotlines for further assessment, and calling 911 on behalf of the case at the case's request, or if the case's described symptoms met criteria for COVID-19-related emergency situations.

In situations where case investigators were required to work with or consult with outside entities, SORT required an internal incident report be filed. These reports were reviewed to provide back-up support to specific cases or to observe trends.

*Scope of Practice*

The scope of investigative duties for case investigators working on the line remains an important issue for SORT. Case investigators were primarily undergraduate students or community volunteers who had undergone a robust, yet limited training program in order to respond to rapidly increasing case surges. The young age and inexperience of many of the case investigators, combined with the wide range of information easily available on the internet led to concerns about what sources of information case investigators could "investigate" outside their case interviews.

For example, a case investigator could in theory search a case's name on social media such as Facebook or Instagram and determine if a case was visiting and posting from restaurants and bars during their estimated infectious window. This was especially concerning as Maricopa County contains Phoenix and Scottsdale, two cities with a significant population of professional athletes and celebrities whose lives are widely telegraphed online, increasing the temptation. Additionally, given the large population of ASU students (119,951 students in Fall of 2019) in Maricopa, some of whom where contracting COVID-19 (and were interviewed by SORT) and the large number of case investigators with an ASU affiliation, there was a chance that case investigators could interview a classmate or colleague.

Given the sensitive information available to case investigators, such as birthdate and address, case investigators *technically* also had the ability to obtain additional information unrelated to COVID-19 case investigations using publicly available online sources. For example, with Maricopa County assessor and Maricopa County recorder records available free online, a birthdate and address could lead a curious case investigator to a cases' property records, valuation, personal liens, and court history. Case investigators could also reverse-look up a case's phone number in an attempt to

identify additional details that were potentially relevant to a case interview (such as a case's workplace).

While the legal duty of case investigators to maintain the confidentiality of case information is clear, the ethical duty of case investigators to refrain from seeking out further, publicly available information that could be useful to the goals of public health to stop the spread of disease is less clear. For example, if a case failed to answer their phone, would it be acceptable to Google the case's name and birthdate and discover the case had a criminal record and was currently serving prison time? Would it be acceptable to search a case's name on Instagram and review their profile to see if they had been dishonest in their interview about not having left their house in the previous two weeks?

While other jurisdictions, especially those in other countries, have utilized alternative sources of information for contact tracing,[34] in the United States, concerns about autonomy, privacy,[35] and a general suspicion of government and public health[36] have impeded the use of even digital contact tracing apps where the user *chooses* to make their data available for COVID-19 tracing explicitly.

ASU SORT concluded that because a standard Qualtrics survey instrument was already in use and many case investigators had only limited training, case investigators should limit the amount of additional information they sought auxiliary to the actual case interview phone-call. ASU SORT provided guidance to case investigators that emphasized the autonomy of cases and respect for case decision making, including about what information they shared. Case investigators were instructed to conduct the interview and not to seek additional information about the case's actual whereabouts or behavior. Acceptable supplemental information that could be gathered elsewhere included confirming the address of a place of business, or the date of a public event attended.

As described earlier, the climate in Maricopa County surrounding COVID-19 has at times been extremely fraught. ASU SORT determined it was important to ongoing case investigation and contact tracing efforts to cultivate a relationship of trust between the case investigator and the case. Ultimately, both the case investigator and the team need to trust that the case is being truthful with their information. This would facilitate the rehabilitation of perceptions of public health as well as prevent case investigator overreach.

**Legal Epidemiology and Future Directions**

ASU SORT experiences responding to the legal landscape during an active pandemic show the need for further research in the area of legal epidemiology. Legal epidemiology explores how laws affect disease and injury in a population.[37] During an active pandemic, with a changing legal landscape it is important to track how law effects pandemic response and effects.

Generally, legal epidemiology faces challenges in drawing causal inferences between law and policy and on the ground public health effects. This research offers a unique view into the decision-making of a public health response team responding to laws. For example, we are limited in our ability to draw causal inferences about how executive orders that enable or inhibit contact tracing affect overall COVID-19 spread in Maricopa County. We can, however, show how the legal and ethical environment impacted the decisions and behavior of the ASU team working on a public health intervention. While this does not give us the direct causal effect between specific policies and COVID-19 in the community, it does help illuminate the complex pathways of legal epidemiology.

Much as case studies on outbreaks look at how illnesses spread in specific, discrete, real-world scenarios, this article looks at how the legal and ethical climate

affected the decisions of a specific team enacting a public health intervention. Legal epidemiology, like traditional epidemiology, should incorporate both broad research on how general characteristics of policy and behavior, as well as short "outbreak" studies that delve deeply into transmission chains and individual behavior. Just as there should be research on how COVID-19 vaccine mandates affect vaccine uptake and case infection rates, legal epidemiology should consider how a law requiring COVID-19 data to be reported to the public health department affects decisions of institutions and individuals implementing public health programs.

It is also essential to understand that laws and policies do not work in a vacuum. What is legal is not always ethical, and vice versa. It is important to consider the scope and ethics of actions taken in response to pandemic policies, especially when addressing public health law, which applies a different balance of autonomy, benevolence, non-maleficence and justice to individual bioethics and the law.

This case study looks at how a combination of laws affect the operation of a specific component of public health intervention: contact tracing. Interventions occur in a complex legal and ethical landscape. This case study highlights the reality of applied legal epidemiology: rather than being directed by a single law, a combination of laws impacts the operation of a specific component of public health intervention: case investigations and contact tracing. In order to conduct case investigations, there are local laws that enable data collection and dissemination to the public health department, and privacy laws that govern data storage and patient slash case contact. On top of that, seemingly unrelated laws can cause additional issues, such as mandatory reporting statutes. The ASU SORT navigated this complex legal and ethical environment to support the COVID-19 response.

The purpose of this paper is to illustrate the challenges the ASU COVID-19 Student Outbreak Response Team faced and the solutions the team implemented to allow future contact tracing efforts to anticipate these difficult on the ground problems in advance of the next pandemic. It is crucial that we learn from the experiences of this past year and acknowledge the actual legal and ethical quandaries faced by case investigators.[38]

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# CHAPTER 6

# CONCLUSION

The goal of this research was the expand on the discussion of contact tracing and public health intervention implementation. Additionally, this research aimed to increase understanding of the gaps between the way research approaches a public health topic and the way that practical implementation of that intervention occurs.

The specific objectives of this dissertation were to:

1. Investigate and describe patterns of research on contact tracing across both scientific (SCOPUS) and legal academic databases over time and show how those patterns were affected by disease outbreaks like COVID-19.
2. Identify and discuss barriers to case investigators eliciting contacts during the first year of the COVID-19 pandemic.
3. Assess legal and ethical hurdles faced by case investigation teams responding to the COVID-19 pandemic.

Each of the main chapters in this dissertation, Chapters Four, Five, and Six, were crafted to address each of these objectives. A summary of the findings from these chapters follows.

## Summary of Findings

Chapter 4: Topic Modeling Across SCOPUS and NexisUni Databases: The Evolution in Research on Contact Tracing Across Scientific and Legal Dimensions Over Time
In preparation for submission to Scientometrics.

This chapter addressed research question 1 by looking at patterns of research on contact tracing across both the SCOPUS and NexisUni databases in order to show the effect of COVID-19 and the differing patterns of research across scientific and legal databases.

- As found in previous studies, COVID-19 is a disruptive phenomenon in scientific academic research. It also a recent driver of a spike in legal academic research publications
    - This disruption extends beyond increased publications and COVID-19 has affected the textual themes of both scientific and legal academic research
- While the COVID-19 disruption is significant, different disease specific topics dominate the scientific and legal academic literature in each decade.
- Legal academic articles differ thematically from scientific academic articles across both the entire corpus and individually in each time period.
    - Outside of the legal specific topics, the legal academic articles also have links to topics including Digital surveillance, Contact Tracing Methods, Expedited Partner Therapy, COVID-19, and HIV/AIDS.
    - The legal focused topic shifts over time from a focus on control to advocacy to surveillance.

Chapter 5: Obstacles to Case Investigation and Contact Tracing: Personal, Structural, and Impassable Barriers to Eliciting Close Contacts for COVID-19 Case Investigation, A Qualitative Study

In preparation for submission to Journal of Public Health Management with coauthors Laura G. Meyer, Jasmine Truong, Mick Salik, Julia Jackman, and Megan Jehn.

This chapter addressed research question number 2 by identifying and discussing barriers to case investigators eliciting contacts during the COVID-19 pandemic through semi structured interviews with 14 case investigators on the ASU Student Outbreak Response Team (SORT).

- Case Investigators interviewed expressed four primary themes related to contact elicitation:

    - Personal Skills and Effort
    - Structural Barriers
    - Trust
    - Impassable Barriers
- Personal skills and effort were individual behaviors that case investigators could deploy to improve their elicitation of contacts. These included:
    - Specific phrases to say
    - Behaving calmly, confidently, and rationally
    - Speaking a common language with the case such as Spanish
    - Listening skills
- Structural barriers were issues outside of the case investigator's control but within the purview of the team and public health response that affected their ability to elicit contacts. These included:
    - Delays in receiving cases
    - Specific questions on the survey instrument that helped or hindered elicitation
- Trust issues were general concerns around trust that impeded case investigator elicitation ability. These included:
    - Trust in the public health system in general
    - Concerns about soliciting
- Impassable barriers were situations where neither case investigators or public health department could act to improve the situation.

Chapter 6: Ethical Issues and Legal Epidemiology in COVID-19 Case Investigation and Contact Tracing: A Case Study of a Large Academic Public Health Partnership

In preparation for submission to the Journal of Law, Medicine, and Ethics with coauthors Laura G. Meyer and Megan Jehn.

This chapter addressed research question 3 which was interested in assessing the legal and ethical hurdles faces by case investigations teams responding to the COVID-19 pandemic. Through experiential description, this chapter delineates the legal and ethical lessons learned by the ASU SORT.

- There were three primary areas where the team had to navigate legal and ethical issues in conducting case investigations and contact tracing:
    - Confidentiality and privacy
    - Mandatory reporting
    - Scope of work
- This explanation of how actual laws and ethical considerations affected program implementation constitutes an applied legal epidemiological case study.

**Synthesis**

In Chapter 4, by looking at articles on contact tracing across both SCOPUS and NexisUni, this research shows that COVID-19 dominates that recent contact tracing literature across both databases. However, the topic models by decade subset also show that this is not an entirely unique phenomenon. Each time period has one or two contagious diseases that make up a significant proportion of the literature. Additionally, both the full corpus and each time slice have legal focused topics that cut across specific diseases.

In Chapter 5, interviews with COVID-19 case investigators show four barriers to contact tracing: personal effort and skills, structural barriers, trust issues, and impassable barriers. While personal effort and skills as well as structural barriers can be

addressed to improve contact elicitation, trust issues and impassable barriers make contact elicitation difficult to navigate.

In Chapter 6, a description and analysis of the legal and ethical issues faced by an active case investigation team show the specific considerations that go into practical implementation. In line with themes identified in the legal literature via topic modeling, confidentiality and privacy were a significant concern. However, mandatory reporting and scope of practice were two issues not identified in the broader contact tracing research.

## Conclusion

This dissertation has explored several elements of contact tracing in response to the COVID-19 pandemic. Research on contact tracing is exploding, with huge amounts of scientific and legal literature being generated. At the same time, the use of contact tracing teams has expanded. Despite this increase in both research on and use of contact tracing, few are looking at the qualitative experiences of case investigators and contact tracers throughout the pandemic. This research shows the barriers reported by case investigators to contact elicitation as well as the hurdles faced by case investigation teams navigating shifting legal environments.

## Limitations

This research is not without limitations. As explained in Chapter 2, this research is occurring at a very specific time and place. COVID-19 research, data, and government response are constantly changing. The data for this research was gathered in May through June of 2021, before the Delta variant and after vaccines were available. The social, political, and legal climate surrounding COVID-19 in Arizona at that specific point in time colors the availability of research to be included in the article corpus, the

attitudes of the case investigator interviewees, and the decisions of the ASU SORT leadership on how to navigate legal-ethical issues.

For Chapter 4, articles in the corpus were limited by the timing of the data collection. Articles from 2020 are still being added to SCOPUS and NexisUni. While it is unlikely these additional articles would have significantly affected the themes uncovered by the topic modeling given the existing sample size, more complete data has the potential to add nuance.

For Chapter 5, the small sample size limited the ability of researchers to run statistical analyses on the interview data. Given the opportunity, a larger sample size of interviews could have allowed for an assessment as to whether expressions of barriers were correlated with other metrics, such as average number of contacts elicited.

**Future Directions**

Future research on contact tracing should continue to assess the experiences of those working in public health during the COVID-19 pandemic. As stated numerous times in this dissertation, the landscape around COVID-19 is constantly changing. Continued research on how public health practitioners are experiencing the pandemic is essential in crafting future responses to rapidly-spreading, contagious disease.

Additional scientometric research at the end of the decade will provide a key snapshot into how disruptive COVID-19 truly was as a research phenomenon. Will it continue to dominate research for an extended period of time, or will it fade by the end of the decade? Additional research on the position of legal academic articles will also serve to further illustrate the thematic differences between scientific academic and legal academic articles.

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# APPENDIX A

# AN QUALITATIVE EVALUATION OF CASE INVESTIGATOR EXPERIENCES ON THE ASU COVID-19 INVESTIGATION TEAM MAIN LINE SEMI STRUCTURED INTERVIEW PROTOCOL

| Research Area | Primary Question | Follow Up Probes |
|---|---|---|
| General | What made you decide to join the ASU COVID-19 Investigation Team? | |
| General *(probe focused on Relational Skills)* | Tell me about a unique experience you have had while on a call/what's been the most unique experience | How did you deal with that? |
| Relational Skills | Walk me through your strategies for building rapport/relationship with the case on the call. | Did you use NURSE?<br><br>If so, how did you use NURSE? |
| Efficacy | How confident do you feel with your skills connecting with cases? | What skills do you most rely on? |
| Efficacy | How confident do you feel with your skills eliciting contacts? | What skills do you most rely on? |
| Impact<br>(Gauging change in understanding, behavior/view/attitudes outside of CI..how CIs carry this out) | How has your CI experience impacted your own behavior with respect to the pandemic? | What about your views on public health? |
| Impact | How does being in a virtual call environment impact your CI experience? | What about your feelings of support? |

# APPENDIX B

## AN EVALUATION OF CASE INVESTIGATOR EXPERIENCES ON THE ASU COVID-19 INVESTIGATION TEAM MAIN LINE IRB APPROVAL

**INSTRUCTIONS**
Complete each section of the application. Based on the nature of the research being proposed some sections may not apply. Those sections can be marked as N/A. Remember that the IRB is concerned with risks and benefits to the research participant and your responses should clearly reflect these issues. You (the PI) need to retain the most recent protocol document for future revisions. Questions can be addressed to research.integrity@asu.edu. **PIs are strongly encouraged to complete this application with words and terms used to describe the protocol is geared towards someone not specialized in the PI's area of expertise.**

**IRB: 1. Protocol Title**: An Evaluation of Case Investigator Experiences on the ASU COVID-19 Investigation Team Main Line

**IRB: 2. Background and Objectives**

2.1 List the specific aims or research questions in 300 words or less.
2.2 Refer to findings relevant to the risks and benefits to participants in the proposed research.
2.3 Identify any past studies by ID number that are related to this study. If the work was done elsewhere, indicate the location.

**TIPS for streamlining the review time:**
✓ Two paragraphs or less is recommended.
✓ Do not submit sections of funded grants or similar. The IRB will request additional information, if needed.

Response:

- The COVID-19 pandemic has necessitated the rapid training and response of large teams of case investigators and contact tracers in order to break transmission chains by eliciting contacts, providing quarantine and isolation guidance, and collecting demographic, symptom, and other data.
- These case investigators have unique experiences of what it is like to actually implement a longstanding public health tool during a modern global pandemic.
- The ASU Case Investigation Unit was established as a public health service in May 2020.

- This study has three research objectives:
  1. Learn about the experiences of the volunteer workforce
  2. Learn how volunteers navigate empathic communication during high stakes contacts in a global pandemic
  3. Learn how the volunteer workforce experience compares to past research foci regarding contact tracing

**IRB: 3. Data Use - What are the intended uses of the data generated from this project?**

Examples include: Dissertation, thesis, undergraduate project, publication/journal article, conferences/presentations, results released to agency, organization, employer, or school. If other, then describe.

Response:

Data will be used for journal publication and research conference presentations. Anonymized, de identified data may also be shared with Maricopa County Department of Public Health per the letter of agreement.

**IRB: 4. Inclusion and Exclusion Criteria**

4.1 List criteria that define who will be included or excluded in your final sample. Indicate if each of the following special (vulnerable/protected) populations is included or excluded:

- Minors (under 18)
- Adults who are unable to consent (impaired decision-making capacity)
- Prisoners
- Economically or educationally disadvantaged individuals

4.2 If not obvious, what is the rationale for the exclusion of special populations?

4.3 What procedures will be used to determine inclusion/exclusion of special populations?

**TIPS for streamlining the review time.**

✓ Research involving only data analyses should only describe variables included in the dataset that will be used.

✓ For any research which includes or may likely include children/minors or adults unable to consent, review content [here]

✓ For research targeting Native Americans or populations with a high Native American demographic, or on or near tribal lands, review content [here]

r research involving minors on campus, review content [here]

Response:

Participants will be selected for inclusion based on their status as current or former volunteers or employees with the ASU COVID-19 Investigation Team. All of these participants will be over the age of 18. Participants will need to have access to a phone and email, and will not be minors, unable to consent, prisoners, or undocumented individuals. This research will not specifically target pregnant women or Native Americans, but it is possible that some participants may fall into either or

both categories. Some of the participants may be students at ASU enrolled in the ASB 484 or USL 216 course and be participants in the student response team for credit. Their participation or refusal to participate in this research will not affect their grade in any way.

**Program Volunteers**

**Inclusion Criteria**

- In possession of a computer, cell phone, and reliable Internet connectivity.
- Complete training program required by the ASU Contact Tracing Unit.

**Exclusion Criteria**

- None

**IRB: 5. Number of Participants**

Indicate the total number of individuals you expect to recruit and enroll. For secondary data analyses, the response should reflect the number of cases in the dataset.

Response:

**Program Volunteers: Until thematic saturation.**

**IRB: 6. Recruitment Methods**

Identify who will be doing the recruitment and consenting of participants.

2 Identify when, where, and how potential participants will be identified, recruited, and consented.

3 Name materials that will be used (e.g., recruitment materials such as emails, flyers, advertisements, etc.) Please upload each recruitment material as a separate document, Name the document: recruitment_methods_email/flyer/advertisement_dd-mm-yyyy

4 Describe the procedures relevant to using materials (e.g., consent form).

✓

Response:

This research will use purposive sampling to select participants for an intensive case study. Participants will be recruited via email and posting in the ASB 484 Course Canvas and the Case Investigation Team Continuing Education Canvas. Participants will be asked to volunteer to engage in one-on-one semi structured interviews. Participation will be voluntary and a decision regarding whether or not to participate will have no effect on a participant's course grade or volunteer status.

IRB: **7. Study Procedures**

7.1 List research procedure step by step (e.g., interventions, surveys, focus groups, observations, lab procedures, secondary data collection, accessing student or other records for research purposes, and follow-ups). Upload one attachment, dated, with all the materials relevant to this section. Name the document: supporting documents dd-mm-yyyy

7.2 For each procedure listed, describe **who** will be conducting it, **where** it will be performed, **how long** is participation in each procedure, and **how/what data** will be collected in each procedure.

Report the total period and span of time for the procedures (if applicable the timeline for follow ups).
For secondary data analyses, identify if it is a public dataset (please include a weblink where the data will be accessed from, if applicable). If not, describe the contents of the dataset, how it will be accessed, and attach data use agreement(s) if relevant.

**TIPS for streamlining the review time.**

8. Ensure that research materials and procedures are explicitly connected to the articulated aims or research questions (from section 2 above).
9. In some cases, a table enumerating the name of the measures, corresponding citation (if any), number of items, sources of data, time/wave if a repeated measures design can help the IRB streamline the review time.

Response:

Participants will be interviewed over Zoom for approximately 30 minutes using a semi-structured interview protocol created by the researchers (see supplemental materials). These Zoom interviews will occur outside the course instruction time for those who are students. Zoom sessions will be recorded using both audio and video with the participants' permission in order to facilitate transcription and coding of the interviews. Students may request that the interview only be audio recorded. Interviews will begin this Spring 2021.

**IRB: 8. Compensation**

8.1 Report the amount and timing of any compensation or credit to participants.
8.2 Identify the source of the funds to compensate participants.
8.3 Justify that the compensation to participants to indicate it is reasonable and/or how the compensation amount was determined.
8.4 Describe the procedures for distributing the compensation or assigning the credit to participants.

**TIPS for streamlining the review time.**

- ✓ **If partial compensation or credit will be given or if completion of all elements is required, explain the rationale or a plan to avoid coercion**
- ✓ **For extra or course credit guidance, see "Research on educational programs or in classrooms" on the following page: https://researchintegrity.asu.edu/human-subjects/special-considerations.**
- ✓ **For compensation over $100.00, review "Research Subject Compensation" at: https://researchintegrity.asu.edu/human-subjects/special-considerations for more information.**

Response:

Participants will receive no monetary compensation for their assistance and time. As volunteers, most understand the nature of the research and will be happy to contribute to generating more knowledge around contact tracing. Students or those eligible for internship credit will receive .5 credit hours towards their internship

hours requirements. Depending on the number of credits a student or intern is registered for, they need to complete 45, 90, or 135 internship hours for the semester.

**IRB: 9. Risk to Participants**

List the reasonably foreseeable risks, discomforts, or inconveniences related to participation in the research.

**TIPS for streamlining the review time.**

✓ Consider the broad definition of "minimal risk" as the probability and magnitude of harm or discomfort anticipated in the research that are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.
✓ Consider physical, psychological, social, legal, and economic risks.
✓ If there are risks, clearly describe the plan for mitigating the identified risks.

Response:

There will be no risk to participants physically, legally, or economically. Some participants may experience some discomfort psychologically or socially when discussing negative experiences with case investigations.

**IRB: 10. Potential Direct Benefits to Participants**

List the potential direct benefits to research participants. If there are risks noted in 9 (above), articulated benefits should outweigh such risks. These benefits are not to society or others not considered participants in the proposed research. Indicate if there is no direct benefit. A direct benefit comes as a direct result of the subject's participation in the research. An indirect benefit may be incidental to the subject's participation. Do not include compensation as a benefit.

Response:

There will be no direct benefit to participants.

IRB: **11. Privacy and Confidentiality**

Indicate the steps that will be taken to protect the participant's privacy.

11.1 Identify who will have **access to the data**.
11.2 Identify where, how, and how long data will be **stored** (e.g. ASU secure server, ASU cloud storage, filing cabinets).
11.3 Describe the procedures for **sharing, managing and destroying data**.
11.4 Describe any special measures to **protect** any extremely sensitive data (e.g. password protection, encryption, certificates of confidentiality, separation of identifiers and data, secured storage, etc.).
11.5 Describe how any **audio or video recordings** will be managed, secured, and/or de-identified.
11.6 Describe how will any signed consent, assent, and/or parental permission forms be secured and how long they will be maintained. These forms should separate from the rest of the study data.

11.7 Describe how any data will be **de-identified**, linked or tracked (e.g. master-list, contact list, reproducible participant ID, randomized ID, etc.). Outline the specific procedures and processes that will be followed.
11.8 Describe any and all identifying or contact information that will be collected for any reason during the course of the study and how it will be secured or protected. This includes contact information collected for follow-up, compensation, linking data, or recruitment.
11.9 For studies accessing existing data sets, clearly describe whether or not the data requires a Data Use Agreement or any other contracts/agreements to access it for research purposes.
11.10 For any data that may be covered under FERPA (student grades, etc.) additional information and requirements is available at https://researchintegrity.asu.edu/human-subjects/special-considerations.

Response:

Raw, identifiable data from interviews (video and audio) will be stored in a password protected, secured, ASU Dropbox computing environment with access limited to the interviewers. Transcripts of the interviews will use alternative identifiers. Interviewers will be the only ones with access to the cross tabulation that links raw interview files with the de-identified transcripts. Consent forms and interview transcript data and coding will be stored in a password protected, secured, ASU Dropbox computing environment where all researchers will have access. No additional encryption, other than the standard ASU Dropbox encryption will be used. The data will be stored for 3 years.

**IRB: 12. Consent**
Describe the procedures that will be used to obtain consent or assent (and/or parental permission).

12.1 Who will be responsible for consenting participants?
12.2 Where will the consent process take place?
12.3 How will the consent be obtained (e.g., verbal, digital signature)?

**TIPS for streamlining the review time.**

- ✓ If participants who do not speak English will be enrolled, describe the process to ensure that the oral and/or written information provided to those participants will be in their preferred language. Indicate the language that will be used by those obtaining consent. For translation requirements, see Translating documents and materials under https://researchintegrity.asu.edu/human-subjects/protocol-submission
- ✓ Translated consent forms should be submitted after the English is version of all relevant materials are approved. Alternatively, submit translation certification letter.
- ✓ **If a waiver for the informed consent process is requested, justify the waiver in terms of each of the following: (a) The research involves no more than minimal risk to the subjects; (b) The waiver or alteration will not adversely affect the rights and welfare of the subjects; (c) The research could not practicably be carried out without the waiver or**

**alteration; and (d) Whenever appropriate, the subjects will be provided with additional pertinent information after participation.** Studies involving confidential, one time, or anonymous data need not justify a waiver. A verbal consent or implied consent after reading a cover letter is sufficient.

✓ ASU consent templates are [here].

✓ Consents and related materials need to be congruent with the content of the application.

Response:

The recruitment email will be sent to participants eligible for inclusion in the study. The recruitment email will include the consent form. If selected for the study, participants will be asked to email back a signed consent form prior to their interview. At the beginning of the interview, the interviewer will confirm they have read the consent document and that they agree to be recorded with audio and visual, or just audio. Participants will be reminded that they can skip any questions or end the interview at any time.

**IRB: 13. Site(s) or locations where research will be conducted.**

List the sites or locations where interactions with participants will occur-

- Identify where research procedures will be performed.
- For research conducted outside of the ASU describe:
  - Site-specific regulations or customs affecting the research.
  - Local scientific and ethical review structures in place.
- For research conducted outside of the United States/United States Territories describe:
  - Safeguards to ensure participants are protected.
- For information on international research, review the content [here].

For research conducted with secondary data (archived data):

- List what data will be collected and from where.
- Describe whether or not the data requires a Data Use Agreement or any other contracts/agreements to access it for research purposes.
- For any data that may be covered under FERPA (student grades, etc.) additional information and requirements is available [here].
- For any data that may be covered under FERPA (student grades, homework assignments, student ID numbers etc.), additional information and requirements is available [here].

**Response:**

The ASU Case Investigation unit researchers, volunteers, and employees operate virtually; there is no physical location.

IRB: **14. Human Subjects Certification from Training.**

Provide the names of the members of the research team.

ASU affiliated individuals do not need attach Certificates. Non-ASU investigators and research team members anticipated to manage data and/or interact with participants, need to provide the most recent CITI training for human participants available at www.citiprogram.org. Certificates are valid for 4 years.

**TIPS for streamlining the review time.**

- ✓ If any of the study team members have not completed training through ASU's CITI training (i.e. they completed training at another university), copies of their completion reports will need to be uploaded when you submit.
- ✓ For any team members who are affiliated with another institution, please see "Collaborating with other institutions" [here]
- ✓ The IRB will verify that team members have completed IRB training. Details on how to complete IRB CITI training through ASU are [here]

Response:

Megan Jehn
Michael Shafer
Alexandra "Lexi" C. White
Laura Meyer
Jasmine Truong
McMilan Salik

PROCEDURES FOR THE REVIEW OF HUMAN SUBJECTS RESEARCH

**General Tips:**

- Have all members of the research team complete IRB training before submitting.
- Ensure that all your instruments, recruitment materials, study instruments, and consent forms are submitted via ERA when you submit your protocol document. Templates are [here]
- Submit a complete protocol. Don't ask questions in the protocol – submit with your best option and, if not appropriate, revisions will be requested.
- If your study has undeveloped phases, clearly indicate in the protocol document that the details and materials for those phases will be submitted via a modification when ready.
- Review all materials for consistency. Ensure that the procedures, lengths of participation, dates, etc., are consistent across all the materials you submit for review.
- Only ASU faculty, full time staff may serve as the PI. Students may prepare the submission by listing the faculty member as the PI. The submit button will only be visible to the PI.
- Information on how and what to submit with your study in ERA is [here]. Note that if you are a student, you will need to have your Principal Investigator submit.
- For details on how to submit this document as part of a study for review and approval by the ASU IRB, visit https://researchintegrity.asu.edu/human-subjects/protocol-submission.

# APPENDIX C

## CONTACT TRACING BARRIERS: QUALITATIVE CODEBOOK

**Code Name:** Personal Skills and Effort

**Detailed description:** CI describes their individual skills or efforts that can be used to more successfully elicit contacts from cases
**Inclusion criteria:** CI mentions a personal thing they do that they think affects their ability to get contacts from the case positively or negatively
**Exclusion criteria:** CI indicated that they could do something but it wouldn't make a difference or that there is some other external factor affecting their ability to elicit contacts
**Typical exemplars:**

"Yeah most of the time when I'm trying to elicit contacts I rely, for the most part, just on being open and transparent with the case say what we're going to use the data for. (Participant 002 CLEANED, Pos. 178)"

"I found it's really helpful to say like "Oh, is there, like, are there any concerns that you have?" like leaving that open ended question for them to like really tell me why like if it's security concerns or if it's that they already informed all their contacts um what have you, there's a million reasons why people don't want to give their contacts. (Participant 004 CLEANED, Pos. 155)"

**Atypical exemplars:**
"The way I phrase it I'm able to I think I'm able to get across that essence of you know humanitarianism and service with my word choice. (Participant 013 Cleaned, Pos. 91)"

**Close but no:**

**Code Name:** Trust

**Detailed description:** CI describes an instance where case trust affects their ability to successfully elicit contacts from cases
**Inclusion criteria:** CI describes trust, opinion of government, opinions on COVID, or other similar feelings that affect their willingness to share contacts.
**Exclusion criteria:** CI focuses on structural changes that can affect opinion of case
**Typical exemplars:**

"I think that sometimes the cases they don't trust what Maricopa county is doing, and so, because of that they don't want to really give our contact information and phone number, because I have experienced some calls where you know they- they know their contacts, but they don't want to provide their phone numbers to me because they don't trust them or something like that. (Participant 006 CLEANED, Pos. 113)"

**Atypical exemplars:**

**Close but no:**

**Code Name:** Structural Barriers

**Detailed description:** CI describes structural issues with how case investigations or public health are conducted that affect their ability to elicit contacts.
**Inclusion criteria:** CI does not have control over the specific thing that affects contact elicitation but it is a theoretically solvable, concrete issue.
**Exclusion criteria:** CI focuses on feelings and perceptions.
**Typical exemplars:**

"I feel more confident the earlier we elicit contacts. Like sometimes if we're eliciting- trying to elicit contact when they tested positive 11 or 12 days ago, there are a lot less likely to give those contacts because they're saying like "Oh, they would have already gotten COVID by now" or "I'm already over in my own isolation, why would I need to give contacts right now, if i'm done with COVID, because you don't know if somebody else still might have COVID or not so." (Participant 002 CLEANED, Pos. 170)"

"Or, sometimes they simply forget because their contacts were from- were a long time ago, and so they don't remember who they came into contact in the time that they have COVID so. (Participant 006 CLEANED, Pos. 114)"

**Atypical exemplars:**

"I will say, like some days, depending on the dates of the cases that we're calling, and you know the timelines, it does change a little bit how much people are willing to share or if they're willing to even you know they can't understand the relevance of relevance of these things sometimes (Participant 012 Cleaned, Pos. 92)"

"I'm happy that the question about how many other people in your household was added to the survey pretty recently, cause I think that really establishes sort of a good base level for contact tracing because then I can just ask, can you name those other people in your household it's really more natural than what was happening before. (Participant 007 CLEANED, Pos. 140)"

**Close but no:**

**Code Name:** No Paths

**Detailed description:** CI describes that there is nothing they can do to help contact elicitation in a situation.
**Inclusion criteria:** CI expresses that nothing can be done to solve the problem
**Exclusion criteria:** CI expresses that the problem is not solvable by them, but that some specific action could fix the issue.
**Typical exemplars:**

"But I guess yeah, like, a big part that played into me not being as confident was not seeing any change, despite changing our way of communicating that question to them.

So I think that's, like, mostly like, the root of my, like, lack of confidence is just, people just seem in general, just not willing to share information like that. So, yeah. (Participant 001, Pos. 66)"

"I once again, I tried to push and it's just the same for every single for every single case, sometimes it works, sometimes it doesn't. (Participant 003 CLEANED, Pos. 136)"

**Atypical exemplars:**

"I do try to ask slightly different probing questions and it's I feel like it's evident when they're just out right not going to share that information, they have no intentions of doing so (Participant 008 Cleaned, Pos. 83)"