# **Contact Tracing: Barriers and Facilitators**

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Contact tracing—the process of identifying, isolating, and managing infected persons and their contacts—is a recognized public health measure for controlling the transmission of infectious diseases. In the context of the COVID-19 pandemic, contact tracing has received intense attention. We provide a brief overview of the history of contact tracing during several major disease outbreaks in the past century: syphilis and other sexually transmitted infections, HIV infection, tuberculosis, Ebola virus disease, and COVID-19. Our discussion on the barriers to and facilitators of contact tracing offers a perspective on societal and institutional roles and dynamics, stigma as a major barrier to effective tracing efforts, and how the nature and epidemiology of the infection itself can affect its success. We explore the evolution and adaptation of contact tracing and provide insights for future programming and research. (*Am J Public Health.* 2022;112(7):1025–1033. https://doi.org/10.2105/AJPH.2022.306842)

ontact tracing is acknowledged as a key strategy for controlling the spread of infectious diseases. It entails locating, isolating, and managing individuals who have an infectious disease (cases), identifying individuals who had contact with the case (contacts), and guarantining such individuals and referring them to testing and other relevant interventions.<sup>1</sup> Timeliness and thoroughness in collecting information are critical to the success of contact tracing. In the COVID-19 pandemic, with hundreds of millions of cases reported to date, it has become critically important to monitor the spread of infection and to interrupt the potential for the ongoing spread of disease.<sup>2,3</sup>

Stigma is a major threat to the efficacy of contact tracing. Stigma is characterized as a negative attitude or behavior toward a person or a group who shares distinguishable traits of a health condition or disease. Stigma can provoke and perpetuate relations of power and control, allowing some groups to devalue others.<sup>4</sup> It is often a response to fear or threat of a serious disease, especially one with highly uncertain and fast transmissibility.<sup>5</sup> Evidence suggests that stigmatizing a medical condition is greatest when the condition is associated with behavior or actions that may be perceived as inconsistent with social norms<sup>6</sup> or when its cause is regarded as one's responsibility.<sup>5,7,8</sup>

# HISTORY OF CONTACT TRACING

We examine the history of contact tracing for five conditions: syphilis and other sexually transmitted infections (STIs), HIV, tuberculosis (TB), Ebola virus disease (EVD), and COVID-19. Furthermore, we explore the adverse consequences of stigma, its drivers, and its implications for health, as well as barriers to and facilitators of contact tracing.

# Syphilis and Other Sexually Transmitted Infections

Syphilis remains a major public health threat worldwide, with an estimated six million new cases each year.<sup>9</sup> It was a leading cause of morbidity and mortality in the first half of the 20th century in the United States.<sup>10</sup> A high incidence of STIs coincided with major historical events, such as the First and Second World Wars, both of which involved movements of large populations. In the mid-1940s, with the establishment of contact-tracing programs in the United States<sup>11,12</sup> and the availability of penicillin<sup>13</sup> as a treatment for syphilis, rates declined for almost 40 years. The HIV epidemic emerged in the late 1980s, with an associated resurgence of syphilis in some populations, and syphilis rates have risen steadily in the United States since 2000.14

Contemporary contact tracing was initially a response for controlling syphilis and later expanded to other STIs. It is often used interchangeably with partner notification in the contexts of STIs and HIV. As part of the partner notification process, a wide range of "partner services"—including health education, counseling, and social services—is offered to index cases and their contacts. Along with reducing prevalence in the community, partner notification plays an important role in reducing reinfection rates and preventing long-term complications of STIs, offers key supports and services, and promotes healthy behaviors among those with STIs.

Contact tracing or partner notification for syphilis and other STIs was important for controlling transmission in the past century but had controversial origins that are particularly relevant to concerns about stigma. At the end of the 19th century, stigmatizing individuals with STIs was fueled by early public health ordinances aimed at controlling a widespread syphilis outbreak across the United States and Western Europe. Such decrees were highly intrusive and punitive to those infected or suspected of being infected. As public health had long associated prostitution with STIs and STI transmission, this placed a great burden on those who engaged in sex work. These were often poor and vulnerable women, and they were made to submit to severe restrictions, including registration and compulsory, and frequently humiliating and unsanitary, medical inspections.

In the United Kingdom, the Contagious Disease Acts of 1864 and 1866<sup>15</sup> mandated regular medical examinations and hospital detention of these women. In the United States, the St. Louis Social Evil Ordinance<sup>16</sup> ordered the detention of women diagnosed with STIs in "social evil hospitals," and the Illinois Board of Health<sup>17</sup> mandated the hospitalization of women of suspected illness and posted signs on their homes warning that a person with suspected venereal disease resided in the home.

By the early 20th century, the development of modern contact tracing was being shaped by social reforms and a public outcry against such stigmatizing ordinances.<sup>18–22</sup> Contact tracing was accompanied by medical advances that included an understanding of syphilis's pathogenesis with the identification of the bacterium that causes syphilis. Extensive public education campaigns were launched, resulting in the expansion of governments funding clinics that offered free, voluntary, and confidential treatment. Public policy reflected such progress. For example, in the United Kingdom, the 1968 and 1974 regulations outlined the process and best practices of contact tracing with an emphasis on protecting confidentiality,<sup>23</sup> and in the United States, the 1938 National Venereal Disease Control Act provided support to STI control programs and made contact tracing a key feature of such programs.<sup>24</sup>

Although contact tracing for STIs has evolved to include linkages to prevention and treatment and care for index patients and their contacts, stigma remains a key barrier. This stigma deters individuals from partner notification and discourages discussion regarding STIs with partners and health care providers to avoid disclosing names to inform contact tracing.<sup>25–27</sup>

### **HIV Infection**

The emergence of the HIV epidemic raised several other important ethical questions regarding partner notification. One such concern centered on the primacy of individual rights versus public health concerns.<sup>28,29</sup> The HIV disclosure debate has been complicated by societal views, particularly the stigmatization of people living with HIV and the criminalization of HIV transmission.<sup>30–32</sup> These issues created conditions that hindered frank, open discussions between people living with HIV and their providers to enable partner notification.

HIV-related stigma has been defined as the "process of devaluation" of people living with HIV and is often triggered by the rejection of "socially unacceptable" behaviors regarding sex and intravenous drug use, both routes of HIV infection.<sup>33</sup> This can be accompanied by discrimination, or the unfair and unjust treatment of an individual based on real or perceived HIV status.<sup>34</sup> Consequently, HIVrelated stigma is a major challenge for disease prevention and has critical implications for physical and mental health outcomes, including depression, feelings of isolation and abandonment, increased substance use, and inconsistent adherence to treatment and care.<sup>34–37</sup>

Furthermore, people living with HIV have faced repressive policies and penalties for the perceived or potential transmission of HIV, and even the nondisclosure of HIV status.<sup>38,39</sup> More than 70 countries have HIV criminal statutes, including 29 in sub-Saharan Africa, 19 in Europe and Central Asia, 14 in Latin America and Caribbean, 11 in Asia-Pacific, and both Canada and the United States in North America.<sup>39</sup> Currently in the United States, 32 states and 2 territories have HIV exposure and disclosure laws that impose criminal penalties, including incarceration.<sup>40,41</sup> In addition, there are statutes that permit correspondence between the justice system and public health authorities about suspected HIV cases.<sup>42</sup> Some states require individuals to sign acknowledgment of potential criminal liability as

part of counseling after testing positive for HIV.<sup>43</sup> Others classify persons who violate HIV laws as violent sex offenders regardless of whether the behavior posed low to no risk of transmission or was motivated by intent to infect or harm.<sup>41</sup> Numerous arbitrary arrests and prosecutions have occurred as a result.<sup>44</sup>

Overall, stigma and discrimination as well as punitive laws and repressive policies have hindered voluntary partner notification.<sup>32,45</sup> In response, rather than adopting a universal strategy, partner notification for HIV has been conducted through a variety of strategies. Known as passive or assisted partner notification, this is accomplished through patient referral, provider referral, contact referral, or dual referral. With each strategy, it is standard practice to refer or link exposed individuals to HIV testing, treatment, and prevention services based on the results of HIV testing.

It should be noted that partner notification for HIV in its various forms has proven to be feasible, acceptable, and effective.<sup>46,47</sup> In the United States, for example, one study showed that 15% of partners tested by partner services were positive for HIV and previously undiagnosed.<sup>48</sup> In Kenya, data from a two-year assisted partner services study indicated that HIV-related deaths were reduced by 13.7% in sexual partners receiving such services.<sup>47</sup> Another study, conducted in Malawi, in which people living with HIV were randomized to one of three methods of partner notification (i.e., passive referral, contact referral, or provider referral) found that 24% of exposed partners who were identified and located went to a health facility through passive referral, 55% through contact referral, and 51% through provider referral.<sup>49</sup> Furthermore, among returning partners, 64%

tested positive for HIV, with 81% of HIV-positive individuals being newly diagnosed.<sup>49</sup>

#### Tuberculosis

Tuberculosis (TB) is the leading infectious disease cause of death globally, claiming 1.5 million lives each year.<sup>50</sup> For most of the 19th century, TB was the leading cause of death in the United States. In the early 20th century, Hermann Biggs, New York City's health commissioner, developed a TB control program that centered on contact tracing efforts, including home visits by health inspectors to screen household members, mapping cases by neighborhood, confinement of cases, and robust community outreach and education campaigns.<sup>51,52</sup> This resulted in a 47% increase in reported TB cases in six years.<sup>53</sup> Contact tracing combined with improvements in living conditions and availability of effective treatments resulted in a steady decline in TB mortality during the 20th century.<sup>54</sup> However, with the advent of the HIV epidemic, a resurgence of TB required the scale-up of contact-tracing efforts for TB cases in the 1990s in the United States and globally.55

Although once considered "elegant suffering" and a transcendent experience, TB was eventually reconstructed as a social disease in the 19th century, when perceived objectionable behaviors, conditions, and groups of people became associated with transmission.<sup>56</sup> For example, although the TB control program established by Biggs in New York City raised health and hygiene awareness, some of its features sparked stigma, fear, and secrecy and highlighted disparities between the rich and the poor. Once an individual was identified as having TB, the person was ordered to isolate or seek clinical services, with different requirements based on economic status. Wealthier individuals had the option to pay a private physician to keep their diagnosis discreet or to seek care at exclusive sanatoriums and were not required to engage in contact tracing. Poorer individuals, conversely, were confined, often against their will, in crowded TB wards at city hospitals or public sanatoriums, resulting in many of the working poor delaying health care in the fear of a TB diagnosis and its repercussions.

As with other stigmatized diseases, individuals diagnosed with TB can experience long-lasting social and economic implications, including exclusion from family and society and job loss because of fear of contagion. The impact of TBrelated stigma on contact-tracing efforts has been well documented. For example, a qualitative study among former TB patients in Thailand found that stigma may be the main barrier to contacttracing investigations among nonhousehold contacts because patients tended to withhold information about workplace contacts, resulting in workplace outbreaks.<sup>57,58</sup> For identified contacts, anticipated TB stigma further hinders the goal of contact tracing by leading to significant delays in diagnosis and treatment <sup>59,60</sup>

Evidence indicates that health education and support programs for individuals with TB, health care providers, and the community have been important for reducing TB stigma and facilitating effective contact tracing.<sup>61,62</sup> The empowerment of TB patients may also be a critical factor in reducing TB stigma, as evidenced by patient TB support clubs in Ethiopia and Nicaragua, which have helped reduce isolation, provide critical counseling, and promote adherence to treatment.<sup>62,63</sup> It has also been suggested that lessons from HIV may be relevant for reducing TB stigma by applying a rights-based approach.<sup>64</sup>

Although important—particularly in view of the availability of effective TB preventive therapy for contacts of those diagnosed with TB and strong recommendations by the World Health Organization in support of contact tracing-contact tracing for TB is, unfortunately, not consistently conducted.<sup>65</sup> In Kenya, a country with a high TB burden, a study reported that close to half of persons with TB were not notified.<sup>66</sup> In Thailand, another study demonstrated that almost half of eligible TB cases did not refer their household contacts to the clinic for further investigation.<sup>57</sup> In Brazil, a study found that less than 20% of contacts of those with TB were reported or assessed, with no information available on uptake of isoniazid preventive therapy.<sup>67</sup>

# Ebola Virus Disease

Since its discovery in 1976, the Ebola virus has resulted in more than 20 outbreaks, mostly in sub-Saharan Africa, with an average case fatality rate of approximately 50%.<sup>68</sup> Containment and control have been critical in controlling such outbreaks, combined with community education, health worker training, and intensive case-finding and contact-tracing efforts.<sup>69,70</sup>

The 2014–2016 Ebola outbreak in the West African countries of Guinea, Liberia, and Sierra Leone was the largest to date, resulting in more than 28 000 total cases and more than 11 000 deaths, surpassing the combined effects of all previous outbreaks.<sup>71–73</sup> In these countries, contact tracing was challenged, with community mistrust manifesting in hostility toward contact tracers, which resulted in new chains of transmission contributing to sustained community transmission.<sup>74</sup> In addition, contact tracers were also stigmatized based on concerns regarding interaction with patients. For those identified as contacts, stigma associated with Ebola discouraged engagement with contact-tracing efforts and seeking care because of the risk of being ostracized by family and other community members. For example, in Liberia, the stigma associated with being a contact occasionally led to fleeing from health authorities.<sup>75</sup> In Sierra Leone, economic and social pressures to maintain livelihood pursuits also drove contacts to evade protocols, increasing the risk of transmission to others.<sup>76</sup> These challenges were also aggravated by the shortage of trained contact tracers as well as inconsistent strategies and techniques for tracking contacts.<sup>74</sup>

Key strategies for mitigating stigma in contact tracing for Ebola include clear and consistent communication between community and health authorities, engagement of community members, and awareness of cultural traditions and practices.77,78 In rural Guinea, a community engagement project involving local leaders and organizations helped raise awareness about Ebola, reduced resistance to humanitarian actors and health personnel, and, thus, improved contact-tracing efforts. Similarly, a survey of epidemiologists who were deployed to West Africa during the 2014–2015 Ebola outbreak noted that cultural awareness of local traditions along with community mobilization and capacity building were essential for successful contact tracing and overall crisis response.79

# COVID-19

To date, more than 500 million COVID-19 cases and more than 6 million deaths

have been reported worldwide.<sup>80</sup> The extent to which contact tracing can mitigate the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19, depends on the magnitude of community transmission. For example, in Singapore, contact tracing was deployed early in the pandemic and yielded early success; this contributed to the detection of approximately 53% of COVID-19 cases.<sup>81</sup> However, in the United States, the sheer number of cases during the various surges of the pandemic rendered effective contact tracing difficult. In June 2020, for example, as some states reported more than 20 000 cases per day, only seven states and Washington, DC, met the Centers for Disease Control and Prevention's recommendation of having 30 contact tracers per 100 000 residents.<sup>82</sup> The surge attributable to the omicron variant has made contact tracing of limited effectiveness, which necessitates the adjustment of such programs.<sup>83</sup>

Community mistrust also prompted public reluctance to cooperate with contact tracers in relation to COVID-19. According to a survey of more than 10 000 US adults in July 2020, 41% of adults said they would not be likely to speak with a public health official by telephone or text message about COVID-19, and 27% would not be comfortable sharing names of potential contacts.<sup>84</sup> A survey in Los Angeles, California, noted that less than 60% of people with COVID-19 agreed to an interview with contact tracers in August 2020.<sup>85</sup>

As noted with other infectious diseases, stigma has been one of the reasons for people's reluctance to disclose contacts' names. For example, a survey among new and established Latinx immigrants in Indiana, which was conducted in April and May 2020, found that immigrants were four times more likely than were nonimmigrants to report that a person should fear disclosing their COVID-19 diagnosis to others and that disclosing such information would make a person feel like an outsider and result in losing friends.<sup>86</sup> Additionally, fear of stigmatization was identified at the beginning of the pandemic as a barrier for the uptake of contact tracing apps because many worried that, if diagnosed, others would be able to identify them through the app's geolocation capabilities.<sup>87</sup> Whether because of privacy concerns, fear of stigmatization, or fear of losing one's job if ordered to quarantine, several studies and news articles have cited these issues as barriers to contact tracing for COVID-19.88-90

At present, approximately 65 countries report having comprehensive COVID-19 contact-tracing programs for all cases, and 62 countries indicate having limited contact tracing for some of their cases.<sup>91</sup> For some countries with comprehensive contact tracing, technology has played a significant role. It is recognized that digital contact tracing has the potential to revolutionize the practice with mobile apps that directly notify contacts of potential exposure through Wi-Fi, Bluetooth, or GPS technology.<sup>92</sup> However, the use of such technology and location-tracking services has elicited privacy concerns in the United States and elsewhere, affecting their acceptance and use.<sup>90,93</sup>

## CONTACT-TRACING FACILITATORS, BARRIERS

Several barriers and facilitators have been identified that influence the feasibility and effectiveness of contact tracing (Box 1). First, the characteristics of the specific condition can affect the feasibility and success of contact tracing. For infections that are transmitted through casual contact (e.g., TB and COVID-19), contact tracing is more difficult because of the large number of potentially exposed contacts and the real possibility of not knowing the identity of such contacts. By contrast, for pathogens transmitted through bodily fluids, such as Ebola and HIV, the identification of contacts is usually more feasible. Additionally, the quarantine required for contacts of those who have COVID-19 or EVD requires strict separation from others for several days, whereas contacts of individuals diagnosed with HIV or TB are not required to be separated from others, but rather need to undergo careful assessment and initiate HIV or TB preventive therapy.<sup>94,95</sup>

In addition, the duration of the disease (i.e., chronic vs acute) and time from exposure to symptom onset (i.e., incubation period) can complicate contact tracing. EVD and COVID-19 are acute infections with short incubation periods ranging from 2 to 21 days. This necessitates prompt identification of contacts to guarantine them and stop cycles of transmission. By contrast, for chronic infectious diseases such as HIV and TB, the longer period from exposure to detection of infection or disease provides contact tracers more time to alert exposed contacts before they may unknowingly transmit the infection to others and allows time to guide such

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### **BOX 1**— Contact Tracing Barriers and Facilitators

Societal	Institutional	Technical (Digital Apps)	Legal and Ethical
Barriers			
Stigma/discrimination Social/economic isolation Xenophobia Fear, secrecy, hostility Privacy and confidentiality concerns Reluctance/apprehension	Limited resources and diagnostic capacity Poor preparation and implementation Low institutional commitment Shortage of trained contact tracers and supervisors Limited resources to support cases and contacts	Privacy and confidentiality concerns Data security Mistrust of app security and effectiveness Concerns with government surveillance Concerns with app efficacy Unregulated online networking	Criminalization of health status Fear of prosecution; selective and arbitrary arrests Potential for stigmatizing press coverage
Facilitators			
Communication and education Community engagement and outreach Community consent; trust between community and public health professionals; transparency Access and availability of quality health care for all	Resource availability Preparedness and planning Institutional commitment Streamlined administration and implementation	Anonymous, protected, and securely stored data Robust and reliable data security and app efficacy Data restrictions—use only for controlling disease transmission Data not to be made available to third-party or commercial use Apps available on voluntary basis	Promotion of social justice and human rights principles Adherence to accepted codes of standards of behavior for medical professionals and health care workers Protective legal framework for confidentiality of health information

individuals to appropriate prevention interventions.

Second, testing, which allows diagnosis and initiation of case investigation, is a crucial first step. This was a challenge early in the COVID-19 response, when there was insufficient SARS-CoV-2 diagnostic capacity and delays in return of results, both major impediments in rapid case identification and effective contact tracing in many parts of the world.<sup>96–98</sup> Additionally, the availability of effective treatment can motivate individuals with suggestive symptoms to seek testing and care. When no treatment was available, as was the case until recently for EVD and COVID-19, individuals may be deterred from getting diagnosed and ultimately delay initiation of contacttracing efforts.

Third, notwithstanding the effect of stigma in limiting the effectiveness of contact tracing, several interventions have been shown to help mitigate stigma. In the case of STIs and HIV, a combination of activism, public support, and social reforms helped bring necessary change to the way these conditions are perceived and to the way public health measures are shaped to restore confidence in the public health system. Partner notification and its referral system have incorporated protections of confidentiality as well as prioritized linking cases and contacts with diagnostic, treatment, and prevention services.<sup>99</sup> Activism helped galvanize the HIV community into social change, creating policies that affirm and uphold the rights of people living with HIV. In combating TB stigma, education and support programs for TB patients, health providers and the broader community have aimed to overcome stigmatizing social norms.<sup>64,65</sup>

## EVALUATING CONTACT-TRACING EFFECTIVENESS

Whether contact tracing is successful at reducing transmission is typically measured by applying epidemiological assumptions to programmatic outcomes. Such measures include the number of case investigations within a specific period, the number of contacts provided by cases and percentage notified of exposure within a specific period, and the number of cases and contacts who complete isolation and guarantine. A study conducted in the United Kingdom used a model of individual-level SARS-CoV-2 transmission based on data from more than 40 000 individuals and simulated the effects of different control measures assuming an estimated reproduction number of 2.6 and the number of contacts that would be newly guarantined per day.<sup>100</sup> The study noted that the combination of isolation and contact tracing with guarantine would lead to the greatest reduction in transmission (64%).<sup>100</sup>

Simulation models of TB transmission examined the effect of household contact tracing in scenarios in which 22% and 50% of TB transmission occurs in the community and household, respectively, and found that household contact tracing is unlikely to influence TB epidemiology.<sup>101</sup> However, the same study found that contact tracing has the potential to initiate preventive therapy that could, in turn, reduce populationlevel TB burden.<sup>101</sup> In the case of EVD, early-stage contact tracing paired with rapid hospitalization of infected individuals has also been found to be effective at impeding epidemic growth by bringing the effective reproduction number below 1-a key indicator of reduced transmission.<sup>102</sup>

In a study conducted in the United Kingdom, a data coding error led to more than 15 000 cases being excluded from contact tracing efforts, leaving 48 000 contacts unnotified. Researchers found that cases included in contacttracing efforts were associated with a 63% reduction in subsequent new infections and a 66% reduction in subsequent COVID-19–related deaths over the six-week period following the coding error.<sup>103</sup>

### **CONCLUSIONS**

The history of contact tracing highlights the important role that individuals, societies, and the health system can play in safeguarding public health. Even with the availability of vaccines and other prevention and treatment tools, contact tracing is necessary to identify exposed individuals at risk and to navigate them to the services they require. Yet, the success of contact tracing hinges on the public's cooperation and engagement and on resources being available to support such efforts. At this moment in history when the global community is acutely aware of the threat that infectious diseases pose to all and when we have learned so much from the COVID-19 pandemic, it behooves us to examine how best to support and conduct contact tracing, how to tailor it to specific conditions, how to ensure the confidentiality of information collected, and how to prioritize those most at risk and provide them with the support they need to adhere to public health guidance. **AJPH** 

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#### **PUBLICATION INFORMATION**

Full Citation: El-Sadr WM, Platt J, Bernitz M, Reyes M. Contact tracing: barriers and facilitators. *Am J Public Health*. 2022;112(7):1025–1033. Acceptance Date: March 13, 2022. DOI: https://doi.org/10.2105/AJPH.2022.306842

**CONTRIBUTORS** 

W. M. El-Sadr conceptualized the article and contributed to the writing and editing. J. Platt and M. Reyes conducted and synthesized the literature research and drafted the article. M. Bernitz reviewed the article, provided input, and contributed to the editing.

#### ACKNOWLEDGMENTS

The authors would like to thank the members of the Contact Tracing Program at Columbia University for their enormous efforts during the COVID-19 pandemic.

#### **CONFLICTS OF INTEREST**

The authors have no competing interests to declare.

#### HUMAN PARTICIPANT PROTECTION

No institutional review board approval was required because this work was not human participant research.

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