

Partners in Prevention: An Examination into the Creation, Operation and Regulation of
Online HIV/STD Partner Notification Programs

A THESIS
SUBMITTED TO THE FACULTY OF
UNIVERSITY OF MINNESOTA
BY

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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF ARTS

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January 2015

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Acknowledgements

As is the case with any grand endeavor of academic prowess (or foolishness), I would like to thank all of the immensely supportive people who have assisted me in completing this thesis project. My committee was comprised of an eclectic group of scholars who each took the time to help me better understand the nuanced issues in public health and bioethics. Susan Wolf has been keenly interested in and supportive of this topic even before I started my time with the Joint Degree Program. Carl Elliott's teaching allowed me to sharpen my analytical lens for bioethics, and he has constantly championed my writing. Simon Rosser has been a wonderful mentor (and employer) in the fields of HIV/STD prevention and online public health. Debra DeBruin has helped me to realize that I am not necessarily the wicked iron fist of public health I so often imagine myself to be. An extra serving of gratitude is owed to Simon and Deb for steering me through these last several months of writing.

My friends and family have been eagerly awaiting the completion of this thesis so that I can no longer use it as an excuse to stay in school, and for that, I thank them for their patience and unending encouragement. Of course, I thank my wonderful parents for their enthusiasm about whatever odd subject I might be studying. And special shout outs go to every group of friends, both students and staff, I have made at the Joint Degree Program, the University of Minnesota Law School, the University of Minnesota Center for Bioethics, and the American Medical Association. A final thanks is especially due to the awesome folks in my life in Minneapolis, Chicago, and around the world.

Dedication

This thesis is dedicated to all of the fantastic people in my life living with HIV.

Abstract

Partner notification serves as a method for tracing sexually transmitted diseases and informing sexual partners about their possible exposure to a communicable disease. While much of the history and scholarly literature about partner notification has focused on its use in the offline context, considerably less work has examined the movement of this public health tool online where growing numbers of people are using social media, dating sites, and hookup apps to meet others for social and sexual purposes. This thesis documents the emergence and development of online HIV/STD partner notification, and it is the first study to critically examine the ethical underpinnings of its practice. Through its application of Nancy Kass's framework for public health ethics, the research presented here demonstrates that online partner notification can be undertaken in an ethically sound manner, yet greater research is needed to understand its effectiveness in an increasingly digitized world.

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INTRODUCTION

The names are a motley assortment of pseudo-adjectives, verbs, and nonsensical homoerotic labels. Grindr, Scruff, Manhunt, Adam4Adam, GROWLr, and Jack'd.¹ To most of the world's population, these titles mean absolutely nothing. But if you happen to be a gay man with easy access to the latest technology, the above names have become a part of your modern vocabulary. In fact, for many gay men, these names have become the key gay touchstones with which to meet and socialize with other gay men.² And how could they not? Gay bars, bathhouses, GLBT coffee shops, and a whole host of other social and sexual venues were once the primary meeting place for gay men to mix and mingle, and quite often, to meet potential sexual partners. The gay community used to have a physical presence, one that was constructed from tangible social encounters. By showing up at a GLBT community event or hanging out with friends at particular gay bar, you communicated who you were, how you identified, and how you wanted to be perceived by the outside world (or for some, just how they wanted to be seen within the confines of that specific physical space). Those days are largely gone now.³ Men still go to gay bars and coffee houses and the like, of course, but no longer with the same

¹ Grindr, Scruff, GROWLr, and Jack'd are GPS-based smart phone and tablet apps, while Manhunt and Adam4Adam are primarily online hookup websites that have been translated into app versions in recent years.

² See, e.g., Jenna Wortham, *How Grindr Is Changing the Way We Connect*, N.Y. TIMES BITS BLOG (Mar. 10, 2010, 1:17 PM), <http://bits.blogs.nytimes.com/2013/03/10/how-grindr-is-changing-the-way-we-all-connect/> (discussing how approximately five million gay men use Grindr for an average of ninety minutes a day, and how the device is changing the dynamics of how gay men meet and interact); see also JAIME WOO, MEET GRINDR: HOW ONE APP CHANGED THE WAY WE CONNECT (2013).

³ See, e.g., B.R. Simon Rosser, William West & Richard Weinmeyer, *Are Gay Communities Dying or Just in Transition?*, 20 AIDS CARE 588, 588–95 (2008).

frequency nor with the same intent. Who needs to go out when you can simply log-on and find exactly what you are looking for at that exact time, and usually, in that exact location?

Finding gay sex in the present day has never been more convenient. Events that transpired during the 2012 London Olympic Games may provide some evidence of this. During the third week of July, just as athletes were pouring into the city to prepare for the international sporting event, a peculiar technical glitch transpired. The GPS-based hookup app, Grindr, collapsed throughout the London metropolitan area.⁴ The company's stated reason for down service was simple: there were too many men trying to log-in.⁵ Between the estimated 350,000 Grindr subscribers residing in and around London, and the influx of thousands of athletes, spectators, and members of the press taking up temporary residence in the city, too many men looking for sexual gratification may have overloaded the servers of the digital dating device.⁶ Service was restored within twenty-four hours following the glitch, and once again the Games and Grindr both returned to bringing the world's people together.

Whether it is on a smart phone, a tablet, or a laptop, the ease with which one can procure male companionship is as simple as the tap of a touchscreen. Such accessibility is nothing new given the saliency of technology in the developed world. Online

⁴ Kevin Burra, *Grindr In London Overloaded By Gay Olympic Athletes?*, HUFFPOST GAY VOICES (July 24, 2012, 10:51 AM), http://www.huffingtonpost.com/2012/07/23/olympic-athletes-london-grindr_n_1695173.html.

⁵ *Id.*

⁶ *Compare id.*, with Alexander Abod-Santos, *No, Olympic Athletes Didn't Crash Grindr*, ATLANTIC WIRE (July 23, 2012), <http://www.theatlanticwire.com/technology/2012/07/no-olympic-athletes-didnt-crash-grindr/54914/> (arguing that it is unlikely the crash of the Grindr system during the initial weeks of the Olympics was due to the influx of athletes and visitors to London).

interactions, whether the participants are gay or straight, have become commonplace fodder for sexual and romantic relationships to begin. While sites like Match.com, eHarmony, and a vast array of online dating forums promise their clientele the chance of finding that Mr. or Ms. Right so many singles dream of, those sites and apps catering to the gay community have harnessed their resources to provide users with Mr. Right Now.

All of this high tech commingling is happening in a rapidly changing social and political landscape. The last two years have been marked by tremendous legal progress in the United States for the gay community as numerous victories have been achieved in the battle for same-sex marriage,⁷ as evidence points to increasing social acceptance of gays and lesbians in the American public,⁸ and as the push for greater civil rights continues.⁹ With respect to the conversations and debates on marriage, the themes of commitment,

⁷ In 2012, Maryland, Maine, and Washington State legalized gay marriage, while in 2013, the states of Rhode Island, Delaware, Minnesota, New Jersey, Hawaii, and Illinois followed suit by legalizing gay marriage in their respective borders. *See Marriage Center*, HUM. RTS. CAMPAIGN, <http://www.hrc.org/campaigns/marriage-center> (last visited Nov. 25, 2013). Furthermore, on the national stage, the U.S. Supreme Court struck down portions of the Defense of Marriage Act in *United States v. Windsor*, 133 S. Ct. 2675 (2013), allowing federal benefits to be conferred to same-sex couples, and declined to speak on the constitutionality of same-sex marriage in *Hollingsworth v. Perry*, 133 S. Ct. 2652 (2013), which effectively upheld California's same-sex marriage law by finding the proponents of Proposition 8 lacked appellant standing to bring the case. *See Adam Liptak, Supreme Court Bolster Gay Marriage With Two Major Rulings*, N.Y. TIMES, June 26, 2013, <http://www.nytimes.com/2013/06/27/us/politics/supreme-court-gay-marriage.html> (last visited Nov. 25, 2013).

⁸ *See, e.g., Bruce Drake, As more Americans have contact with gays and lesbians, social acceptance rises*, PEW RES. CTR. (June 18, 2013), <http://www.pewresearch.org/fact-tank/2013/06/18/as-more-americans-have-contacts-with-gays-and-lesbians-social-acceptance-rises/> (last visited Nov. 25, 2013).

⁹ At the time of this writing, the Employment Non-Discrimination Act (ENDA), which would provide basic workplace protections against discrimination based on sexual orientation and gender identity, is up for a vote in the U.S. House of Representatives having already passed in the U.S. Senate. Many commentators point to overwhelming support across U.S. population for the passage of this law. *See Andrew Gelman, Polls say ENDA has majority support in every congressional district*, THE MONKEY CAGE: WASH. POST BLOG (Nov. 20, 2013, 3:55 PM), <http://www.washingtonpost.com/blogs/monkey-cage/wp/2013/11/20/polls-say-enda-has-majority-support-in-every-congressional-district/>.

monogamy, and fidelity have provided a glossy sheen to the campaign on just what gay marriage will look like and what its existence will mean in modern day America, producing an overarching message that gay marriage will be exactly like heterosexual marriage: boring and (un)remarkably normal.¹⁰ However, it is important to be honest about the sexual and relational foundations that trigger these bonds, especially when it comes to gay men. Sex is widely available at any time and in any place regardless of who you are and your relationship status, with a significant portion of gay men choosing relationships that allow for greater sexual freedom and negotiation with their primary partners.¹¹ In fact, the casual nature of gay sex is so pervasive that according to many, sex is the gay handshake.¹² Monogamy has become monogamish,¹³ and the online world has become a sexual playground.

It is not all fun and games, however. HIV/AIDS and other sexually transmitted disease (STDs) have come along for the ride. Despite the decreased incidence of new cases of HIV/STDs in men who have sex with men (MSM) for nearly a decade following the horror of the HIV/AIDS epidemic of the 1980s and 1990s, HIV/STDs are once again

¹⁰ For a discussion on the political maneuvering of the gay marriage campaign across the United States, see Molly Ball, *The Marriage Plot: Inside This Year's Epic Campaign for Gay Equality*, ATLANTIC (Dec. 11, 2012, 7:05 AM), <http://www.theatlantic.com/politics/archive/2012/12/the-marriage-plot-inside-this-years-epic-campaign-for-gay-equality/265865/>.

¹¹ See Jeffrey T. Parsons et al., *Non-Monogamy and Sexual Relationship Quality Among Same-Sex Male Couples*, 26 J. FAM. PSYCHOL. 669, 671–72 (2012) (noting that in their study, 47.2% of men self-identified being in some form of non-monogamous relationship).

¹² Michael Joseph Gross, *Has Manhunt Destroyed Gay Culture?: A cost-benefit analysis of our quest to get laid*, OUT (Aug. 4, 2008), <http://www.out.com/entertainment/2008/08/04/has-manhunt-destroyed-gay-culture>.

¹³ See Jeffrey T. Parsons et al., *Alternatives to Monogamy Among Gay Male Couples in a Community Survey: Implications for Mental Health and Sexual Risk*, 42 ARCHIVES SEXUAL BEHAV. 303, 303–12 (2013).

climbing in the gay community,¹⁴ as are rates of unprotected sex,¹⁵ and public health officials and researchers are dumbfounded as to how to curtail this disturbing resurgence of disease.¹⁶ Numerous reasons have been proposed for what might be the culprit or culprits driving this rise in disease transmission, and one reason always factored into these analyses is the presence and increasing dominance of the online hookup sector.¹⁷ With online environments being so efficient, and the sexual exchanges so brief, the opportunities for spreading disease are replete.

In an attempt to counteract the deleterious health effects of online hookups, HIV/STD prevention itself has moved online, adapting a familiar practice by taking it out of the public health clinic and transplanting it into the digital sphere. Partner notification has been practiced in some form for close to two hundred years, serving as a method for tracing disease transmission and informing sexual partners about their possible exposure to a communicable disease. While online partner notification has been in place for close to ten years, nothing has been explored in terms of its ethical undertaking.

The aims of online partner notification programs are noble and necessary. They help to guard the public's health by notifying individuals about a sexual tryst that might

¹⁴ See CDC, FACT SHEET: HIV AND YOUNG MEN WHO HAVE SEX WITH MEN 1–4 (2012), available at http://www.cdc.gov/HealthyYouth/sexualbehaviors/pdf/hiv_factsheet_ymmsm.pdf; see also CDC, *Gay and Bisexual Men's Health: Sexually Transmitted Diseases*, CDC.GOV (Sept. 24, 2010), <http://www.cdc.gov/msmhealth/STD.htm>.

¹⁵ See CDC, *HIV Testing and Risk Behaviors Among Gay, Bisexual, and Other Men Who Have Sex with Men—United States*, 62 MORBIDITY & MORTALITY WKLY. REP. 958 (2013) (reporting the increasing rates of unprotected anal sex in the gay community between 2005 and 2011).

¹⁶ See, e.g., Monique Duwell, *HIV Infections Rising in Young Gay Men in Urban US*, ABC NEWS (Jul. 24, 2012, 7:00 AM), <http://abcnews.go.com/blogs/health/2012/07/24/hiv-infections-rising-in-young-gay-men-in-urban-us/> (noting the troubling rise of HIV infection in MSM and the various reasons medical practitioners and public health researchers suspect to be driving this trend).

¹⁷ Gross, *supra* note 12.

have resulted in an STD, and encourage those individuals to seek testing, treatment, and counseling services. Despite their continued existence, online partner notification programs have received little attention within the scholarly literature. As the overflowing cornucopia of online options for one to identify sexual partners continues to expand, examining the ways in which the technology behind these sites and apps can be utilized to extend the reach of public health services is critically important.

At the forefront of this online public health endeavor has been two organizations: one is a for-profit company that produces sexually-explicit media and hosts a world-renowned hookup site, and the other is a nonprofit organization that develops online tools to promote sexual health education. Both have created sophisticated and efficient technological instruments for tech-savvy users to communicate important information about their health to past sexual partners through two different online partner notification services.

This thesis is the first ethical analysis of online HIV/STD partner notification programs, which also distinguishes the ethical nuances of online partner notification from offline partner notification methods. The discussion that follows is analyzed through the application of Nancy Kass's ethical framework for public health programs, demonstrating that both online and offline notification systems are ethically sound endeavors that address HIV/STD prevention in two-fold manner: first, they attempt to notify sexual partners of their risk of exposure to an STD, and second, they contribute to efforts at the population-level to reduce the incidence and prevalence of HIV and other STDs. Despite there being relatively little existing empirical data about the effectiveness of partner

notification as a whole to warn sexual partners and, overall, to decrease disease rates, online partner notification represents a step forward for contacting partners through digital avenues that were simply impossible twenty years ago. In a world where platonic, romantic, and sexual relationships are being initiated and fostered through websites and apps, the infectious agents that can be transmitted through the offline interactions that manifest from these virtual connections requires public health to intervene in a similarly technologically adept manner. As technology redefines how human beings meet for all varieties of relational bonds, the ways in which HIV/STD prevention is conducted must also be redefined, but done so in an ethical manner that can best protect the interests and liberties of the patients and sexual partners involved in the partner notification process.

Part I provides the necessary historical background on partner notification. Contemporary partner notification was borne from the national campaign to eradicate syphilis during the 1930s and 1940s, but made an uncomfortable comeback to the public consciousness as the HIV/AIDS epidemic of the 1980s and 1990s tore through the lives of marginalized communities in the United States. Part II describes how partner notification is undertaken in the modern day, and how online partner notification falls into this collection of health services. Part III discusses the origins of online partner notification and how the growth of online social media and hookup sites provided a unique forum for public health scientists and practitioners to trace sexual networks online, simultaneously allowing researchers and clinicians to trace STD transmission routes as well. Two very different organizations have been at the forefront of the online partner notification wave. Online Buddies, Inc.—the maker of a hookup site and overseer of a gay sex industry

brand—has had a long history of public service by providing public health organizations with access to important data on the sexual behavior of gay men, while also taking a leading role in the formulation and implementation of online partner notification. The second company, YTH, is a sexual health education and research nonprofit that creates online instruments and apps for the promotion of sexual and reproductive health. YTH's online partner notification tool, inSPOT, has garnered tremendous attention from both inside and outside the public health community because of its simple, user-friendly design. Part IV applies the Kass framework for public health ethics to online partner notification and offline partner notification, identifying where these systems converge and diverge in terms of the benefits and burdens these two related processes bestow on the parties taking part in partner notification. While the threats to privacy and confidentiality, liberty and self-determination, and justice exist in either form of notification, the benefits of each system outweigh these burdens given the good that can come from patients successfully notifying their sexual partners about a sexual encounter where a disease exposure may have taken place. Part V concludes this thesis, discussing how future partner notification systems may look, and offering final thoughts on the analysis contained herein.

The work that is presented here is a mixture of historical, legal, public health, and bioethics research, and complimented by a series of informal interviews and discussions with public health workers,¹⁸ academic researchers,¹⁹ and employees from Online

¹⁸ Four public health workers who work in HIV/STD prevention, education, and partner notification were interviewed for this study. These interviews were conducted in the summer of 2010, and questions focused on the partner notification services of their respective health department, and their working relationships with both Online Buddies and YTH.

Buddies.²⁰ Some of this work is also guided by my own professional and personal experiences gained as a project coordinator for HIV/STD prevention grants conducted out of the University of Minnesota School of Public Health, Division of Epidemiology and Community Health. Because those who were kind enough to donate their time and insight to this project continue to have active careers in public health and public health research, their identities shall not be disclosed. Having been in contact with the University of Minnesota's Social and Behavioral Sciences IRB since the beginning of this project, human subjects review was determined to be unnecessary for this thesis because the primary entities under study are online partner notification systems and the companies that run them, not the people who undertake this area of disease prevention. This work was generously supported by a 2010 Consortium Research Grant awarded by the Consortium on Law and Values in Health, Environment, and the Life Sciences.

¹⁹ Six public health researchers provided insight on their work or interactions with Private. These discussions took place at the 2012 International AIDS Conference in Washington, D.C. All of these researchers are affiliated with major researcher universities or nonprofit research organizations in the United States, and their primary area of research is in HIV/STD prevention and research.

²⁰ The primary person interviewed for this thesis was David Novak, Senior Public Health Strategist for Online Buddies, Inc. Mr. Novak generously offered me the opportunity to interview him at his office in Cambridge, Massachusetts on August 10, 2010.

I. THE HISTORICAL BACKGROUND OF PARTNER NOTIFICATION

a. In Search of an End to Syphilis

Partner notification traces its origins back to Renaissance Europe and the appearance of a disease that was up until that time unheard of in Western society. The disease was syphilis, and it would lay siege on the European continent for centuries following its discovery in 1494.²¹ Once it was learned that the illness was transmitted via sexual contact sometime in the early sixteenth century,²² efforts were launched to impede the dissemination of disease by regulating the source of infection.²³ Those persons found to be carrying the disease were often denied all access to facets of public life, removed from their homes, banished from cities, or placed in hospitals designated to treat syphilitics.²⁴ No member of society received more condemnation for the wellspring of syphilis than the prostitute. As the disease maneuvered its ways across all segments of the European population from century to century, the body of the female prostitute became the prime target for applying public health interventions.²⁵ For instance, in France, the medical screening and control of prostitutes was known as *réglementation* (French for “regulation”), and prostitutes were required to register with the government and agree to

²¹ John Firth, *Syphilis—Its Early History and Treatment until Penicillin and the Debate on its Origins*, 20 J. MIL. & VETERANS’ HEALTH 49, 49–50 (2012).

²² Most historical accounts of syphilis note that the disease was discovered to be sexually transmitted not longer after the disease first appeared in Europe; however, the first official documentation citing syphilis to be a sexually transmitted disease was reported in 1514 by Johannis (Giovanni) de Vigo, surgeon to Pope Julius II. *Id.* at 50.

²³ See GEORGE ROSEN, A HISTORY OF PUBLIC HEALTH 73 (1958).

²⁴ *Id.* at 74.

²⁵ *Id.* at 97.

bi-monthly health examinations,²⁶ while in Great Britain, Parliament passed the Contagious Disease Acts of 1864 and 1866 which “required the compulsory registration and police supervision of all prostitutes plus regular examinations and even compulsory hospital detention.”²⁷

The United States embarked on similar escapades to rid the American population of syphilis’s grip. Under the auspices of the Social Hygiene Movement—a politically powerful group of moral crusaders concerned with ridding American society of its physical and moral ills²⁸—model legislation was drafted and lobbied for at the state level to make prostitution a “morality crime” rather than a crime of “public order” in order to stem syphilis rates.²⁹ Furthermore, the Social Hygiene Movement was behind the creation

²⁶ See, e.g., *France and Prostitution: On the Game*, ECONOMIST, July 12, 2012, <http://www.economist.com/node/21558612>.

²⁷ M.W. Adler, *The Terrible Peril: A Historical Perspective on the Venereal Diseases*, 281 BRIT. MED. J. 206, 206 (1980).

²⁸ The social hygiene movement combined the technical goals of physicians to eradicate disease and the social goals of purity activists to remove the “social evil” of prostitution. The concretization of this movement was not an easy one, however. Physicians, led by the social reformer Dr. Prince A. Morrow of New York, focused their campaign on changing the moral conduct of U.S. society in order to enhance the sexual continence of men which they saw as the great failing of contemporary America, and the primary vehicle for spreading venereal disease. These doctors called for the use of blunt propaganda and shaming to influence behavioral change. Purity crusaders, however, sought institutionalized transformation in the form of legal intervention and political change that would create and expand the influence of women in politics and social life, and bring about a new class of professional women determined to invoke “maternalistic” social policy. Under Morrow, the two movements would set aside their differing visions to work on the common goals they shared: removing the threats of prostitution and venereal disease. In 1913, the American Social Hygiene Association would be formed, led by the former President of Harvard University, Charles Eliot (who turned down the ambassadorship to England to assume the organization’s leadership). See John C. Burnham, *The Progressive Era Revolution in American Attitudes Towards Sex*, 59 J. AM. HIST. 885, 885–908 (1973).

²⁹ Kristin Luker, *Sex, Social Hygiene, and the State: The Double-Edged Sword of Social Reform*, 27 THEORY & SOC’Y 601, 615 (1998) (“Once prostitution had been legally transformed into the crime of ‘promiscuous sexual intercourse,’ there was now an expanded network of people whose property, status, livelihoods, or licenses were at risk should they be accused of tolerating these activities newly defined as prostitution. As a result, new groups apart from traditional reformers had been created with a stake in monitoring such behavior.”).

and passage of the federal Chamberlain-Kahn Act of 1918 which allocated federal dollars for the creation of venereal disease control programs in the U.S. geared towards the “detention, isolation, quarantine, or commitment to institutions”³⁰ of women suspected to be prostitutes. All of these attempts at removing the threat of syphilis from the U.S. through intrusive actions and moral condemnation proved futile, however. But in the wake of these morality laws, the rise of New Deal politics and the ardent need for progressive social reform legislation inspired a more scientifically-driven epidemiological plan for pursuing syphilis eradication that would be implemented across the country. Thomas Parran, the sixth Surgeon General of the United States, would be responsible for this medical movement, and it was from his work that partner notification would find its place in the arsenal of disease control and prevention.

b. The Emergence of Partner Notification in the U.S.

Thomas Parran was an ardent advocate of syphilis control, and more broadly, communicable disease prevention, having come to this line of work in the 1920s as the chief of the U.S. Public Health Service’s (PHS) Division of Venereal Diseases.³¹ During his time with PHS, Dr. Parran created several committees to undertake comparative studies of syphilis treatment, and called for enhanced scientific rigor and government funding for strategies to reduce the prevalence and incidence of syphilis around the country.³² His work in venereal disease control and public health reform would catch the

³⁰ Public Health & Research (Chamberlain-Kahn) Act of 1918, 40 Stat. 845, 887 (1918).

³¹ See Lynne Page Snyder, *New York, the Nation, the World: The Career of Surgeon General Thomas J. Parran, Jr., MD, (1892-1968)*, 110 PUB. HEALTH REPS. 630, 631 (1995).

³² *Id.*

eye of New York Governor Franklin D. Roosevelt, who, three years into his first term as president would appoint Parran to the role of U.S. Surgeon General in 1936.

As Parran ascended to his new national role, he took the opportunity to use his influence to launch a national campaign to counteract syphilis once and for all; a plan he laid out in his treatise on the country's syphilis epidemic, *Shadow on the Land*. The text was a combination of economic, social, and epidemiological statistics regarding the details of the syphilis epidemic in the U.S., as well as providing foreign accounts of how venereal disease was mitigated and treated in the European context.³³ Parran provided his own insight into the nation's struggle to overcome a persistent malady that had taken the lives of men, women, and children across all socio-economic classes. The crux of the book focused on Parran's "Plan for Action," a pronounced call to arms for both the private and public sectors to invest resources into removing the foreboding bacteriological presence encroaching on the country. First, Parran advocated for increased effort to locate syphilis by strengthening screening systems at hospitals across the country.³⁴ Second, he argued for the need for greater public funding to assure the provisions of medical treatment for all persons infected with syphilis, dividing the financial burden across national, state, and local health departments.³⁵ And third, Parran called for greater educational training for American private physicians about syphilis in

³³ The chapters of *Shadow on the Land* clearly layout the topical areas he found to be of greatest importance, and are as follows: (I) What Is Syphilis?, (II) An Old Plague—The Great Pox, (III) Today's Problem: Prevalence & Trend, (IV) American Beginnings, (V) Scandinavian Experience, (VI) Great Britain & Continental Europe, (VII) The Contemporary Scene: Official Action, (VIII) White Man's Burden, (IX) The Contemporary Scene: Syphilis & the Job, (X) Prostitution & the Ethical Outlook, (XI) Stumbling Blocks, (XIII) A Platform for Action, (XIII) First Things First, and (XIV) The Personal Equation. See THOMAS PARRAN, *SHADOW ON THE LAND* (1937).

³⁴ *Id.* at 247–59.

³⁵ *Id.* at 259–62.

order to raise awareness in the medical community about the effects of venereal disease, empowering doctors to become vehicles for education and information within the general public.³⁶ *Shadow on the Land* provided a well-conceived though seemingly simple account of how to solve America's syphilis crisis, and with a resounding stamp of approval from critics and the general public alike,³⁷ the book provided Thomas Parran with the momentum he needed to legally enforce his ideas.

Swayed by Parran's foresight and passion, along with the growing support of the U.S. public, President Roosevelt and both houses of the U.S. Congress quickly saw to the passage of the National Venereal Disease Control Act of 1938, of which Surgeon General Parran was the chief architect.³⁸ Under the Act, fifteen million dollars (roughly \$242 million in today's currency) was allocated over three years to support the creation of state anti-venereal disease measures including the establishment of diagnostic and treatment facilities, training of health care workers, and the bringing together of state and national level programs into concert with one another.³⁹ Built around the regulatory powers inherent in PHS, Parran developed a plan under the Venereal Disease Control Act that

³⁶ *Id.* at 262–67.

³⁷ See ALLAN M. BRANDT, *NO MAGIC BULLET: A SOCIAL HISTORY OF VENEREAL DISEASE IN THE UNITED STATES SINCE 1880*, at 142 (1987).

³⁸ See 42 U.S. § 25(a)-(d) (1938). An immensely influential component of Parran's persuasive political nature had to do with the economic issues he presented to fellow politicians regarding the costs of prevention versus the much higher costs of treating venereal disease after the fact. See BRANDT, *supra* note 37, at 143–46.

³⁹ 42 U.S. § 25(a)-(d) (1938) (“[A]ssisting States, counties, health districts, and other political subdivisions of the States in establishing and maintaining adequate measures for the prevention, treatment, and control of the venereal diseases; for the purpose of making studies, investigations, and demonstrations to develop more effective measures of prevention, treatment, and control of the venereal diseases.”).

was grounded in his earlier work.⁴⁰ Parran's plan called for a concerted effort at the local, regional, and national levels to screen citizens for syphilis, identify those who tested positive for the disease, and provide them with prompt therapy.⁴¹ Yet the most critical component of this strategy was a practice that was revolutionary for its time, which called for the tracing of sexual partners of infected individuals so they too could be tested for syphilis and treated should they test positive.⁴² It was here that the disease prevention method of partner notification would be born, and it would serve as the hallmark of Dr. Parran's decades of research and public health practice in his continuous fight to warn the American citizenry of its susceptibility to STDs.

Thomas Parran's medical and administrative goals to address syphilis and remove the moralized, stigma-laden policies of the social hygiene's movement would prove to be a success. Between 1938 and 1940, state-supported clinics nearly doubled from 1,750 to 3,000, while serological tests for venereal disease grew by 300% during the same time period due to the federal funding and the infrastructure provided by the National Venereal Disease Control Act.⁴³ Controlling and decreasing the syphilis epidemic seemed at long last within reach, and Parran would become an iconic figure for this achievement during his time as Surgeon General, as well as long after his tenure in political office

⁴⁰ This plan evolved from this three major points discussed in *Shadow on the Land* in order to prescribe a more precise form of medical intervention.

⁴¹ See Allan M. Brandt, *The Syphilis Epidemic and its Relation to AIDS*, 239 SCI. 375, 378 (1988).

⁴² See Lawrence O. Gostin & James G. Hodge, Jr., *Piercing the Veil of Secrecy in HIV/AIDS & Other Sexually Transmitted Diseases: Theories of Privacy & Disclosure in Partner Notification*, 5 DUKE J. GENDER L. & POL'Y 9, 22 (1998).

⁴³ Brandt, *supra* note 41, at 378.

would come to an end.⁴⁴ As the funding for syphilis control would begin to dwindle by the early 1940s, the advent of penicillin would come to be shown as a safe and efficacious cure for the illness.⁴⁵ While prevention efforts were still needed, the burden of venereal disease was dramatically reduced by the newfound miracle drug.⁴⁶

c. A New Disease and a New Controversy

With the arrival of penicillin, and the further development of other antibiotics to treat many bacterial STDs, the efficacy of partner notification in the battle against infectious disease was of little concern to most. But in the summer of 1981, the documentation of *pneumocystis carinii pneumonia* in gay men living in Los Angeles revealed the presence of another illness that would soon draw partner notification back into the public health discussion.⁴⁷ HIV/AIDS would exact a traumatizing blow to the American population, and the illness was portrayed as impacting those groups where the disease was believed to be most concentrated, including homosexual men, Haitians, and hemophiliacs. Just as syphilis had been the scourge of prostitutes and “fallen men” during the early twentieth century, the disease-laden stigma of HIV/AIDS would arouse suspicions towards those minority groups most burdened by the virus.⁴⁸ And as scientists and physicians began to unearth the characteristics of the virus and understand its modes of transmission, partner notification would be reasserted as a means to trace and inform

⁴⁴ See Snyder, *supra* note 31, at 632.

⁴⁵ See ROSEN, *supra* note 23, at 341.

⁴⁶ *Id.*

⁴⁷ See CDC, *Pneumocystis Pneumonia—Los Angeles*, 30 MORBIDITY & MORTALITY WKLY. REP. 1, 1–3 (1981) (documenting the unusual occurrence of this rare illness in five men living in California).

⁴⁸ For a wonderful study on the cultural impact of HIV/AIDS on American society, and in particular, the minority groups who were targeted as harboring the disease, see PAULA A. TREICHLER, *HOW TO HAVE THEORY IN AN EPIDEMIC* (1999).

sexual partners and drug-sharing partners possibly exposed to HIV, but this time, with considerably more contestation from the lives this public health measure touched.

Because HIV and the symptoms it manifested were distinctly different than other STDs that had been scrutinized by public health instruments, the disease presented newfound challenges for health care workers seeking to screen patients, identify those found to be HIV positive, and then work with those infected individuals to contact their exposed partners.⁴⁹ The call by public health departments to encourage increased testing in groups deemed to be at a higher risk for contracting the virus was met with considerable outrage, especially from a gay community that was incredibly suspicious of the true intentions of city and state governments that had for so long denied them access to rights and services.⁵⁰ For example, in 1985, the City of San Francisco attempted to put in place a partner notification pilot program where the city's public health department asked bisexual men to provide the names of their sexual partners in order to notify these men and women of their exposure to HIV.⁵¹ The gay community vociferously opposed the project, calling it "Orwellian" because of concerns about patient privacy, confidentiality, and the handing over of sensitive information to the government that

⁴⁹ HIV is markedly different than other STDs because of its comparative latency periods. While acute latency (the time when the virus first enters the system and is rapidly reproducing) lasts for up to four weeks, clinical latency (in which the patient may be asymptomatic) can go for as long as ten years. If an individual is asymptomatic during both acute and clinical latency, and is not regularly tested for HIV, it may be difficult for clinicians to pinpoint the exact timing of infection and to ascertain which of the patient's partners have been exposed. *See Stages of HIV Infection*, AIDS.GOV (Dec. 19, 2013), <http://aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/hiv-in-your-body/stages-of-hiv/>.

⁵⁰ Ronald Bayer & Kathleen E. Toomey, *HIV Prevention and the Two Faces of Partner Notification*, 82 AM. J. PUB. HEALTH 1158, 1159–60 (1992).

⁵¹ RONALD BAYER, PRIVATE ACTS, SOCIAL CONSEQUENCES 124 (1989).

could be used for potentially discriminatory actions in housing, employment, and other social services.⁵²

At the heart of the opposition to identify new infections and trace their sexual connections was the proposition by state governments to pursue mandatory HIV antibody testing. While those within government in favor of these measures saw them as effective ways to better understand and control the HIV/AIDS cases within their respective state borders, voices on the other side of the aisles predicted a testing backlash where persons of highest risk for testing positive (and also the greatest risk for transmitting HIV) would be scared off by mandatory screening for fear of discrimination, stigma, or personal harm.⁵³ Exacerbating the fears of those against mandatory testing was the growing discussion on the confidentiality of those tests as staunch disagreement arose over named reporting of HIV-positive diagnosis to state health departments.⁵⁴ Once again, proponents of named reporting deemed this an opportunity to initiate medical care and social services for HIV-positive persons, to provide the state with robust data about the impact the disease was having in specific communities, and to better support partner notification efforts that were significantly limited without this information.⁵⁵ Yet leaders in the gay community, and even some officials in public health departments, were concerned about how truly confidential these data would be and that ulterior motives were in actuality

⁵² *Id.*

⁵³ AMY L. FAIRCHILD, RONALD BAYER & JAMES COLGROVE, *SEARCHING EYES: PRIVACY, THE STATE, AND DISEASE SURVEILLANCE IN AMERICA* 176–78 (2007).

⁵⁴ *Id.* at 182–89.

⁵⁵ *Id.*

driving named reporting that could easily lead to AIDS registries or the quarantine of positive persons.⁵⁶

In states such as Minnesota, Wisconsin, and Colorado—states where the brunt of the epidemic was less felt—mandatory named reporting was implemented.⁵⁷ It is questionable as to whether there were any negative effects from the implementation of name-based reporting in states that adopted this system. In Colorado, for example, HIV testing by gay men declined following the adoption of the reporting laws,⁵⁸ but subsequent data revealed that testing rates were higher than in states without named reporting (e.g., California).⁵⁹ A follow-up study conducted in Colorado found that only one percent of men identified the new laws as their reason for delaying testing.⁶⁰

In the states of California and New York, however, the legislatures steered from named reporting because of the potential breakdown in cooperation that would possibly emanate between public health departments and the communities they served.⁶¹ But as the epidemic continued into the 1990s, and as the tumultuous discussion of named reporting vacillated in many states, the CDC itself sought to remove the patchwork of reporting and notification standards existing across the country by pushing for named HIV reporting.⁶² And despite what opponents feared, the data suggested that named

⁵⁶ *Id.*

⁵⁷ *Id.* at 177.

⁵⁸ BAYER, *supra* note 51.

⁵⁹ Franklyn N. Judson & Thomas M. Vernon, Jr., *The Impact of AIDS on State and Local Health Departments: Issues and Few Answers*, 78 AM. J. PUB. HEALTH 387, 391 (1988).

⁶⁰ Grant N. Colfax & Andrew B. Bindman, *Health Benefits and Risks of Reporting HIV-Infected Individuals by Name*, 88 AM. J. PUB. HEALTH 876, 878 (1998).

⁶¹ FAIRCHILD, BAYER & COSGROVE, *supra* note 53, at 177–81.

⁶² *Id.* at 197–98.

reporting did not actually deter persons from testing for the virus.⁶³ Amidst a bitter back-and-forth argument with states, and between the states and the CDC, the CDC released final recommendations in 2005 that would finally settle the argument for patients, states, and the federal government.⁶⁴ All states must now participate in name-based reporting of HIV surveillance data.⁶⁵

Given that the political debates surrounding HIV named reporting occurred first, and because many of the arguments (on both sides) were similar for mandated reporting and partner notification, much of the same uproar occurred pertaining to mandatory partner notification for HIV. Many health officials and activists argued for the good that could come about from legally requiring partner notification,⁶⁶ and some states actually proposed such actions.⁶⁷ However, intense opposition to mandatory partner notification has continued to remain a salient presence in partner notification debates, and “most programs and state educational initiatives [have] centered on individuals protecting themselves from infection.”⁶⁸ While the disclosure of one’s HIV status to sexual partners has always been a thorny point of research and public health practice, public health

⁶³ *Id.* at 199.

⁶⁴ Letter from Dr. Julie L. Gerberding, Director of the CDC, Recommendation for Adoption of Confidential Name-Based Surveillance Systems to Report HIV Infections (July 5, 2005), available at http://www.cdc.gov/hiv/pubs/070505_dearcolleague_gerberding.pdf.

⁶⁵ *Surveillance Brief: Terms, Definitions, and Calculations Used in CDC HIV Surveillance Publications*, CDC.gov (June 19, 2013),

<http://www.cdc.gov/hiv/statistics/recommendations/terms.html> (“As of April 2008, all 50 states, the District of Columbia, and 6 U.S. dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, the Republic of Palau, and the U.S. Virgin Islands) had implemented confidential name-based HIV infection reporting.”).

⁶⁶ See Chandler Burr, *The AIDS Exception: Privacy v. Public Health*, ATLANTIC, June 1997, available at <http://www.theatlantic.com/magazine/archive/1997/06/the-aids-exception-privacy-vs-public-health/308779/>.

⁶⁷ *Id.*

⁶⁸ ROSEN, *supra* note 23, at 72.

officials have done their part in recent years to emphasize the personal obligation of HIV-positive persons to notify their past and future partners of their exposure to the virus.⁶⁹

II. THE PRACTICE OF PARTNER NOTIFICATION

a. Offline Partner Notification

Partner notification exists as one of many activities that fall within the suite of services known as partner services. Partner services programs provide an array of medical and social outreach programs intended to identify partners believed to be exposed to an STD through sexual activity, or in the case of HIV or hepatitis, injection drug use, or other blood-borne pathogens, and then puts partners in contact with testing and treatment services designed to decrease or stop the spread of infection. Partner services typically include free HIV/STD testing, free or affordable medical treatment, emergency occupational and non-occupational post-exposure prophylaxes (where appropriate), psychological counseling, and social services for those exposed to HIV, including referrals for substance abuse, sexual violence, and other related physical and mental health problems. Partner notification, of course, is an integral component to this system in order to identify who has been exposed, get those exposed to be tested, and where an HIV or other STD diagnosis is confirmed, get people into appropriate care. Once a person tests positive for one or more STDs, this individual becomes what is known in the public health lexicon as the index patient from which future (or past)

⁶⁹ See, e.g., *Do You Have to Tell?*, AIDS.GOV (Aug. 23, 2009), <http://aids.gov/hiv-aids-basics/just-diagnosed-with-hiv-aids/talking-about-your-status/do-you-have-to-tell/> (recommending that persons recently diagnosed with HIV talk with past and current partners about their serostatus and the need to seek testing and counseling).

exposures can be traced. It is at this point that partner notification begins as the index patient, with or without the assistance of a disease investigator, embarks on identifying and contacting those partners with which he has had sexual contact during the estimated duration of the infection.⁷⁰ Partner notification has traditionally fallen into one of four strategies: provider referral, self-referral, contract referral, and dual referral. Each of these strategies will be discussed below.

Provider referral, as the name suggests, is when a disease investigator directly informs the index patient's partners of their possible exposure to an STD, and then provides the partner with information on services where he or she can access testing and treatment. During this communication, it is the responsibility of the disease investigator to maintain confidentiality and not reveal the name of the index patient, nor offer any information that would allow the partner to ascertain the identity of the patient. What is key to provider referral is that responsibility of making the notification falls entirely on the disease investigator, with the patient serving no role except for providing the name and the contact information of the partner.⁷¹ Furthermore, while the phrase "provider referral" may insinuate that the personnel is in fact a qualified nurse or physician, the individual assisting the patient may be a disease investigator, an administrator, a

⁷⁰ While certain STDs provide little biological information on how long a person has been infected, others, such as syphilis and HIV, are often characterized by defined symptoms and signs of infection that allow health care providers to estimate how long a patient has had the disease and when transmission roughly took place.

⁷¹ See, e.g., CDC, *Recommendations for Partner Services Programs for HIV Infection, Syphilis, Gonorrhea, and Chlamydial Infection*, 57 MORBIDITY & MORTALITY WKLY. REP. 1, 27–28 (2008).

community health worker, or other person specifically trained to undertake partner notification.⁷²

According to the CDC, provider referral notification is the most effective single strategy for contacting partners.⁷³ While illnesses such as chlamydia and gonorrhea are considered less severe and can often be asymptomatic for considerable periods of time, syphilis and HIV are diseases where timing is of the essence for diagnosis and treatment, and provider referral has been shown to be the swiftest means for getting in touch with potentially exposed partners.⁷⁴ Although few studies have been implemented to directly compare the effectiveness of the different partner notification strategies, two studies specifically about HIV partner notification have examined the success of provider referral versus self-referral by randomly assigning index patients to one or the other. In one study, index patients assigned to provider referral were 6.5 times more successful in notifying partners than those index patients who undertook self-referral methods.⁷⁵ The second study, though less robust in its results, still demonstrated that provider referral was a more effective means of partner notification than was self-referral.⁷⁶

As provider referral is entirely the task of administrative or health care workers, self-referral places the onus of carrying out partner notification solely on the index

⁷² This was the case for several of the persons associated with public health departments that were interviewed for this study.

⁷³ CDC, *supra* note 71, at 28.

⁷⁴ *Id.*

⁷⁵ Suzanne E. Landis et al., *Results of a Randomized Trial of Partner Notification in Cases of HIV Infection in North Carolina*, 326 NEW ENG. J. MED. 101, 101–05 (1992).

⁷⁶ N.E. Spencer et al., *Partner Notification for Human Immunodeficiency Virus Infection in Colorado: Results Across Index Case Groups and Costs*, 4 INT’L J. STD & AIDS 26, 26–32 (1993).

patient who then informs his respective partners to seek out testing and treatment. In order to ensure that an index patient has the capabilities and correct information to properly inform partners, index patients are often given written instructions known as contact slips or referral cards to give to their partners.⁷⁷ Contact slips include the diagnosis, contact information for available clinics and health care services, recommended treatments, and instructions on what to do until treatment is sought (e.g., abstain from sexual activity). Once again, because of confidentiality, the index patient's name and identifying information never appears on these cards.⁷⁸ Referral cards have been shown to substantially improve notification outcomes for patients pursuing self-referral, and index patients using these cards have had considerably lower rates of re-infection than when referral information is absent.⁷⁹

Given that self-referral results in fewer referrals, it is a means of partner notification that is pursued when the illness is of a less serious nature. However, research has shown that self-referral amidst an HIV diagnosis can be successfully pursued if the index patient's partner is their primary partner or a regular sexual partner,⁸⁰ or in

⁷⁷ CDC, *supra* note 71, at 29.

⁷⁸ *Id.* at 30.

⁷⁹ Patricia Kissinger et al., *Patient-Delivered Partner Treatment for Male Urethritis: A Randomized, Controlled Trial*, 41 CLINICAL INFECTIOUS DISEASES 623, 623–29 (2005).

⁸⁰ See, e.g., Philip Batterham, Eric Rice & Mary Jane Rotheram-Borus, *Predictors of Serostatus Disclosure to Partners Among Young People Living with HIV in the Pre- and Post-HAART Eras*, 9 AIDS & BEHAV. 281, 281–87 (2005); K.M. Sullivan, *Male Self-Disclosure of HIV-Positive Serostatus to Sex Partners: A Review of the Literature*, 16 J. ASSOCIATED NURSES AIDS CARE 33, 33–47 (2005).

situations where the index patient feels a strong sense of responsibility to personally informing his partners of their possible risk.⁸¹

The last two forms of partner notification are an amalgam of provider and self-referral notification. Contract referral notification is an arrangement between the provider and the index patient whereby the patient chooses to notify a select number of partners on his own, with the disease investigator contacting those partners the patient is uncomfortable contacting. Under this system, the patient agrees to notify the partners within a specific timeframe. Should the patient fail to notify this select group, the disease investigator will then initiate notifications. Finally, dual referral notification involves the patient and investigator working together to notify partners. This form of partner notification is usually implemented in situations where there is concern on the part of the index patient that a negative reaction will result from the notification (e.g., anger or physical violence). In these scenarios, the presence of a disease investigator can decrease tensions by providing immediate counseling and information to allay any fears by either the patient or partner, while the inclusion of the index patient in the process can offer the partner a more personable and affirming experience which can lead to improved health outcomes for both parties.⁸² The success of these two last forms of partner notification have not been researched, but their application is warranted in those circumstances where it is believed they can be more effective than either provider referral or self-referral pursued on their own.

⁸¹ See, e.g., P.M. Gorbach et al., *Don't Ask, Don't Tell: Patterns of HIV Disclosure Among HIV Positive Men Who Have Sex with Men with Recent STI Practising High Risk Behaviour in Los Angeles and Seattle*, 80 *SEXUALLY TRANSMITTED INFECTIONS* 512 (2004).

⁸² CDC, *supra* note 71, at 30.

b. Online Partner Notification

Up until the early 2000s, partner notification contacts were done via telephone or face-to-face appointments at local public health/medical clinics. In the last decade, a considerable amount of partner notification has moved online. Internet-based partner notification programs operate under the same provider/self-referral divide as offline systems, and therefore it is only the medium that has changed. Whether it is the index patient or the disease investigator making the contact, the system is fairly straightforward. For certain sites, the user logs into the system by selecting the city or state where they (or their sexual partners) reside. The system then prompts the user to select from six to ten different styles of e-postcards that can be sent out, with each card having an assortment of fonts, images and personal messages that can be tailored to the tastes of the user. From there, the user selects from a series of drop down menus pertaining to the following information: the STDs for which they have tested positive, their gender, the gender of their sexual partners (male/female/both), their age, and their zip code. The user then enters the email addresses of persons with whom they have had sex in the past six months, and is then provided with the option of entering their own personal email address or selecting the “Send Anonymously” category. Finally, the user enters their age and race/ethnicity. Afterwards, the system prompts the user to preview the e-postcard they have drafted and to check the email addresses of those individuals receiving the email. The user hits “send” and the partner notification process is completed for the index patient. Partner notification systems located on hookup sites operate under similar protocols, with the only difference being that email addresses (or other contact

information) may not have been previously exchanged, and thus postcards/emails are sent to the online screen names of the sexual partners.

III. THE EMERGENCE OF ONLINE PARTNER NOTIFICATION

a. Syphilis in San Francisco

In 1999, a microbe that had been at one time considered on the brink of eradication began its triumphant return to the public health main stage. While syphilis had been steadily on the decline for decades following the introduction of penicillin, this ancient disease would rear its infectious head in a modern day online world. Researchers at the University of California, San Francisco and officials with San Francisco's Department of Public Health received a report regarding cases of early-stage syphilis diagnoses in two gay men who had informed public health workers that they had each met the majority of their sexual partners in a chat room on AOL.⁸³ With this information in hand, the researchers used an online marketing firm to utilize the very same chat room to disseminate the message that if users had met sexual partners in that electronic venue, they should seek medical examinations for syphilis and other STDs.⁸⁴ From the efforts of the researchers and health workers, five related syphilis cases were identified and dozens of other men were screened for the disease.⁸⁵ Not only had the partner notification system via the Internet proven useful for locating unidentified cases and encouraging others to

⁸³ Jeffrey D. Klausner et al., *Tracing a Syphilis Outbreak Through Cyberspace*, 284 JAMA 447, 447 (2000).

⁸⁴ *Id.* at 448.

⁸⁵ *Id.*

seek STD screenings, it was the first time a disease’s transmission route was able to be traced because of the online activity reported by the men who were involved in the outbreak.⁸⁶ Over the next two years, syphilis would surge ahead in its unwelcome comeback through similar online exchanges, and other cities around the country were able to replicate the initial finding of the San Francisco group.⁸⁷ It was during this time period that formalized online partner notification systems would come into being.

b. inSPOT

The website for YTH.org is a delightfully simple and seemingly carefree online presence. Black and white photos of adolescents enjoying their youth cover the page, adorned with three short words: “new”, “now”, and “next”.⁸⁸ YTH, which stands for “youth + tech + health,” is the reincarnation of Internet Sexuality Services (i.e., ISIS), a nonprofit organization that has sought to “advance youth health and wellness through technology” since 2001.⁸⁹ The projects currently under development with YTH demonstrate quite clearly that this intersection of health promotion and technological advancement lie at the core of the organization’s focus. For example, there is “Today is 4 Tomorrow,” a Tumblr page for high school students of color that communicates messages regarding healthy living, unplanned pregnancy prevention, mental health information, and more.⁹⁰ Or, there is SexINFO, the first sexual health text-messaging

⁸⁶ *Id.* at 449.

⁸⁷ See, e.g., CDC, *Primary and Secondary Syphilis Among Men Who Have Sex with Men—New York City, 2001*, 51 MORBIDITY & MORTALITY WKLY. REP. 853 (2001); CDC, *Outbreak of Syphilis Among Men Who Have Sex with Men—Southern California, 2000*, 50 MORBIDITY & MORTALITY WKLY. REP. 117 (2001).

⁸⁸ YTH: YOUTH + TECH + HEALTH, yth.org (last visited Jan. 23, 2014).

⁸⁹ *Id.*

⁹⁰ TODAY IS FOR TOMORROW, todayis4tomorrow.tumblr.com/ (last visited Jan. 23, 2014).

program for adolescents and teenagers that allows individuals to text simple questions about sexual health to outreach workers who then provide answers or recommendations for relevant services.⁹¹ But the instrument YTH is most renowned for is inSPOT.org, an online partner notification tool available in fifty states, twelve specific metropolitan areas, and currently translated into three languages. InSPOT⁹² is one of the most utilized and well-known online partner notification system in the United States, and its success in part stems from the fact that it grew directly out of the syphilis outbreak that instigated tracing STD transmission online in the first place.

In 2004, amidst rising rates of syphilis in the gay community throughout the country, YTH and the San Francisco Public Health Department conducted a needs assessment and held several discussions within the San Francisco gay community to better understand how men communicated with their sexual partners about the diagnosis of an STD.⁹³ Most men indicated that they were comfortable with informing their primary partners, either on their own or with the help of a disease investigator, but when it came to notifying casual partners, men stated that they rarely conveyed this information, if at all.⁹⁴ However, the men in these community discussions noted that if there were a simple, convenient, and anonymous way in which to relay this bad news to a

⁹¹ SexINFO, www.sextextsf.org (last visited Jan. 23, 2014).

⁹² InSPOT stands for “internet notification services for partners or tricks.” *San Francisco Unveils Internet-Based STD Partner Notification Service*, ADVOCATE, Oct. 8, 2004, available at <http://www.advocate.com/news/2004/10/08/san-francisco-unveils-internet-based-std-partner-notification-service-13973?page=full>.

⁹³ Deb Levine et al., *inSPOT: The First Online STD Partner Notification System Using Electronic Postcards*, 5 PLOS MED. 1428, 1428 (2008), available at <http://www.plosmedicine.org/article/fetchObject.action?uri=info%3Adoi%2F10.1371%2Fjournal.pmed.0050213&representation=PDF>.

⁹⁴ *Id.*

casual sex partners, they would use it.⁹⁵ From these discussions, inSPOT was developed and tested with considerable community buy-in in the San Francisco area, and since 2004, the number of inSPOT sites developed for state and city public health departments have grown exponentially.⁹⁶

The design of a typical inSPOT site is very intuitive. Each individual inSPOT site is connected to the main inSPOT portal page, which is divided into two sections: “Tell Them” and “Get Checked.” The “Get Checked” portion of the site is designed specifically to help users locate clinics in close proximity where they can be tested for STDs and receive medical treatment in the event they test positive for an infection. Users can also click on separate links within this section to learn about all of the various STDs that one can acquire, whether each STD is treatable or curable, and the medical treatments one can receive to either cure or control the disease. The “Tell Them” section is the partner notification component of inSPOT. In order to send a message to a sexual partner, a user must select the language of the message, and then choose the applicable region (city or state) from a dropdown menu that then links users to the city/state-specific inSPOT site. Once inside the locally tailored inSPOT system, users have the opportunity to select one of six pre-designed e-cards that serve as the templates for the messages partners will receive. Each e-card contains one of several messages. Some messages are playful: “I got screwed while screwing, you might have too. Get checked for STDs if you haven’t recently,” or “You’re too hot to be out of action. I got diagnosed with an STD

⁹⁵ *Id.*

⁹⁶ InSPOT sites now exist for all fifty states along with city-specific sites for Chicago, Washington, D.C., New York City, Philadelphia, Portland, San Diego, San Francisco, Seattle, and Los Angeles (County). *See Testing Services*, INSPOT.ORG, <http://inspot.org/Testing/tabid/63/language/en-US/Default.aspx> (last visited Jan. 24, 2014).

since we played. You might want to get checked too.” Other messages are more serious. “I’m so sorry. I didn’t know I had STDs when we were together. You should get tested.” No matter which card is chosen, all cards offer the opportunity to include an optional personalized message. Every user must then select the STD they have been diagnosed with from a preselected dropdown menu, and then enter the email addresses of up to six partners. Finally, the user can choose to enter his or her email address or to send the message anonymously. Once the user has previewed the entire e-card, the message is then sent to the selected partners.

For each new location that hires YTH to create a special inSPOT system tailored to the needs of that region, the business model is very straightforward. All city and state public health departments that approach YTH pay for the system through local, state, and federal funds allocated for partner notification services. While the original inSPOT site in San Francisco cost approximately \$50,000, YTH then worked with an engineering firm to create a content management instrument that made future inSPOT replications considerably easier and more cost effective.⁹⁷ By 2010, the cost for creating an inSPOT site was around \$15,000, and maintenance fees per year were close to \$3,000 depending on the customizations requested for individual sites.⁹⁸ These customizations include detailed information regarding clinics where one can seek testing and treatment, regional maps to indicate the location of clinical services, banner advertisements to direct users to the site, etc. YTH then continuously works with each jurisdiction to maintain up-to-date clinic hours, clinic locations, contact information, programmatic changes for each public

⁹⁷ *Id.*

⁹⁸ *Id.*; Interviews with public health workers in Minnesota, Washington, Chicago, and New York (July-Aug. 2010).

health department, as well as regular testing of the inSPOT email address from which anonymous emails are sent (getchecked@inspot.org) and the subject line of the e-cards in order to prevent them from being captured by email spam filters.⁹⁹

In terms of relationships with public health departments, YTH and inSPOT have been a resounding success. The public health workers interviewed for this piece spoke highly of their interactions with YTH. Given its nonprofit status, and the organization's commitment to public health, health departments have been impressed by YTH's knowledge of STD prevention and treatment services, and its ability to produce a user-friendly online notification system that is also affordable. In a time when many state and federal funds for public health outreach has dwindled, YTH's price consciousness has been especially appreciated. Perhaps the greatest asset to YTH has been its founder and executive director, Deb Levine. Levine has been dedicated to working in sexual health services since the early 1990s when she helped to found Columbia University's student-oriented health Q&A site, Go Ask Alice!, a site that has been widely acclaimed for its direct, accurate, and accessible health guidance, receiving high praise from health practitioners and scholars alike.¹⁰⁰ In addition, Levine's work in the area of online sexual health has been cited in federal reports, and widely published in academic journals and news sources.¹⁰¹ And at Levine's side is a cadre of former public health workers,

⁹⁹ Levine et al., *supra* note 93, at 1429.

¹⁰⁰ Go Ask Alice! has been featured in numerous academic articles noting the accuracy of its sexual health information, its popularity as a resources for adolescents and families in search of up-to-date online health information, and its usefulness as a health education and health promotion site. See Go Ask Alice! *according to the research*, GOASKALICE.COLUMBIA.EDU (Sept. 10, 2013), <http://goaskalice.columbia.edu/media-moments>.

¹⁰¹ For a full bio and list of Deb Levine's work and accomplishments, see *Deb Levine-President and Founder*, YTH.ORG, <http://yth.org/about/team/#deb> (last visited Jan. 24, 2014).

engineers, and young community activists who help YTH to run effective digital health projects.

c. **Manhunt**

Just as inSPOT was beginning its attempts to reduce STD transmission on the West Coast of the United States, similar efforts to use the Internet and digital communications to quell rising rates of STDs on the East Coast were taking shape. But the partner notification movement that was launched in this section of the country was not entirely driven by academics or public health officials as was the case in California. It would be a private, for-profit online company dedicated to providing a forum for gay men to meet sex partners leading the change.

Around 2001, two businessmen by the names of Larry Basile and Jonathan Crutchley had derived a modicum of success with a gay singles telephone chat line that catered to the Boston and New York markets.¹⁰² Although neither Basile nor Crutchley had any technical expertise,¹⁰³ they took a leap of faith and decided to take their small chat company online. This leap was not without some foresight. For several years, starting in the mid-1990s, the growing online environment had become the perfect place for men—gay, bisexual, questioning—to meet, socialize, and cruise for sex, starting with “M-4-M” chat rooms on general interest sites such as AOL, and then moving to specific sites created by the gay community itself, such as Gay.com.¹⁰⁴ The site Basile and

¹⁰² Gross, *supra* note 12.

¹⁰³ See *About Us: Founders*, ONLINE BUDDIES.COM, <http://online-buddies.com/about-us/founders/> (last visited Jan. 24, 2014) (“Jonathan worked as a real estate broker in Boston before meeting business partner Larry Basile” “Prior to his founding of OLB, Larry owned and operated historic gay bar Fritz and the attached Chandler Inn hotel in Boston’s South End.”).

¹⁰⁴ Gross, *supra* note 12.

Crutchley founded was to be quite different than those that had preceded it, though. The company they created from which to base their new venture was Online Buddies, Inc., and the gay hookup site it supported was aptly named Manhunt. Manhunt would go on to become a gay business behemoth because unlike previous gay-specific websites and chat rooms it focused on one thing only: sex. What Manhunt provided was a fast and efficient environment where paying members could maintain profiles to post nude (and clothed) photos, list their physical attributes, their preferred sex acts and fetishes, and allowed users to sort the profiles of others according to their physical characteristics and libidinal interests. Like most online social networking sites, members use a messaging system, video chat, and a smartphone app version of Manhunt to stay in contact with potential “suitors.” Separate from the Manhunt site itself, Online Buddies, Inc. has been involved in a multitude of other endeavors geared towards the gay community, including the production of gay porn, sponsorship of circuits parties and bar promotional events, and perhaps surprisingly, partnering in health outreach and research.

Since its creation, Online Buddies has always employed one individual dedicated to public health activities who, on behalf of the company, enters into partnerships with community based organizations, public health departments, and academic researchers. Online Buddies’ involvement has ranged from promoting safer-sex awareness events to placing banner advertisements within the Manhunt site to recruit members for various studies dealing with HIV/STD prevention research, and more generally, gay men’s health. To bolster the health-oriented projects within the company, Online Buddies hired a former CDC employee by the name of David Novak in 2008 to oversee future aspects

of Online Buddies' involvements in the health community. Novak would be responsible for implementing the company's online partner notification system. His stewardship of Online Buddies' notification program was no accident, given that from 2004 to 2007, David served as the syphilis elimination coordinator for the Massachusetts's Department of Public Health, and during that time, he worked closely with Online Buddies to construct online HIV/STD outreach services to Manhunt members, with the online partner notification system being the crown jewel of this work.

The Manhunt partner notification system obviously serves the same role as the inSPOT system, but its reach and operation are quite different. While inSPOT is open to anyone male, female, gay, or straight, Manhunt's partner notification system is restricted only to Manhunt members.¹⁰⁵ Because Manhunt and almost all other hookup sites and mobile apps require members to establish online profiles with unique screen names or handles, users very seldom exchange email addresses or other specific contact information, therefore, the means of contact utilized by inSPOT is not possible. Furthermore, partner notification messages sent within the online Manhunt environment are not initiated by Manhunt members on their own. Instead, Manhunt works with disease investigators in every state who are trained in the CDC's partner notification guidelines, and it is these specialists who use designated "Partner Notification" profiles set up within the main Manhunt system to send out messages notifying one's sexual partners that they have been exposed to an STD. In the event that a Manhunt member tests positive for an

¹⁰⁵ While the Manhunt partner notification system is only open for Manhunt members to contact other Manhunt members, those individuals (either the index patient or his partners) can certainly work with health care workers to undertake other forms of online partner notification or offline partner notification.

STD, that member can then work with a disease investigator at a designated clinic¹⁰⁶ to notify sexual partners met on Manhunt by providing the handles of those men. As David Novak has stated, the benefit of the Manhunt system is that by having a public health clinic confirm the positive diagnosis, and then initiate the contact, there is less opportunity for false information to be disseminated, as compared to inSPOT where it is the patient himself sending the message and where there is no confirmatory mechanism in place. No matter what the strengths (or weaknesses) of the Manhunt partner notification system may be, it has been a useful tool for Manhunt members and has been widely championed by Novak.

IV. THE ETHICS OF ONLINE PARTNER NOTIFICATION

a. The Ethical Landscape of Offline Partner Notification

Since its incorporation into the national strategy for targeting and curtailing the transmission of sexually transmitted diseases, partner notification has raised many ethical questions and dilemmas about the power of the state to compel private citizens to warn sexual partners about their risk of exposure. As Thomas Parran told the National Conference of Venereal Disease Control in 1936, “Every case must be located, reported, its source ascertained and all contacts then informed about the possibility of infection,

¹⁰⁶ Manhunt maintains a directory of clinics in each state where members can get tested for STDs, and then work with disease investigators in that clinic should a test confirm an infection. *See Testing Resources*, MANHUNTCARES.COM, <http://www.manhuntcares.com/gettested/> (last visited Jan. 24, 2014).

provided with a Wasserman test, and if infected, treated.”¹⁰⁷ This passion for disease eradication is commendable, but in its actualization and operation in the public sphere, the goals of public health are set against concerns to the individual. Furthermore, at the heart of partner notification—and a feature that has defined it for so many years—there arises a conflict of fundamental principles: when an STD is introduced into a sexual relationship between two (or more) people, the rights of one individual must, to some degree, be balanced against the rights of others, because “infected individuals cannot maintain their privacy while at the same time making their partners fully aware of their risk of exposure.”¹⁰⁸

These are complicated problems with which the fields of public health, ethics, and law continue to struggle. The core ethical tensions at play are the rights of one individual (the index patient) versus the rights of another individual (the sexual partner), and the individual good versus the common good in protecting the public’s health, and the scholarly literature on partner notification has teased out the various layers that comprise these overarching challenges.

One tension lies in the privacy interests of the index patient and the interests of his sexual partners. For the index patient, there is a strong ethical claim to maintain the privacy of his medical diagnosis and his health status, and in many situations, his own identity, in order to guard against real or perceived threats that could take the form of

¹⁰⁷ Bayer & Toomey, *supra* note 50, at 1159 (providing excerpts from unpublished CDC documents of a speech by Thomas Parran about his national campaign to end venereal disease in the United States).

¹⁰⁸ Gostin & Hodge, Jr., *supra* note 42, at 62 (citing Gabriel Rotello, Editorial, *AIDS Is Still an Exceptional Disease*, N.Y. TIMES, Aug. 22, 1997, at A23 (“The rights of infected people must be balanced against the right of all people to protect themselves.”)).

stigmatization, discrimination, or bodily harm.¹⁰⁹ These very same concerns exist for sexual partners who themselves may wish to be shielded from displaying the intimate details of their lives and their personal health to disease investigators, public health workers, or in the event of a breach, friends or the broader public, yet who also have a right to being informed of the risk to which they may have been exposed.¹¹⁰ This right to know buttresses a partner's autonomy by giving them the option to seek out testing and clinical care, should it be needed, and also allows them to assess their past sexual behaviors and inform their future sexual health choices, which may help them to avoid future exposures or prevent the transmission of an existing infection to others.¹¹¹ Moreover, within this push-and-pull between the interests of individuals, there are concerns about how to deal with the information that is being conveyed. How are the results of an HIV or STD test being communicated between individuals, health care entities, and the state? Who has access to these data and how is it being used outside of the notification process?

Another tension exists between the rights of the individual versus the protection or enhancement of the public's health and well-being. Partner notification is not only concerned with aiding index patients in their efforts to notify sexual partners. It is also focused on the larger goal of reducing the incidence and prevalence of HIV/STDs in entire communities, and in total, the general population. Therefore, protecting individuals from unwanted and unwarranted intrusions into their private lives, yet simultaneously

¹⁰⁹ *Id.*

¹¹⁰ *Id.* at 65 (“Balanced against the claims of infected persons to privacy are the equally compelling claims of their partners to be informed of the risk.”).

¹¹¹ *Id.*

wanting them to participate in partner notification in order to advance the health of the public, can present a challenge for this avenue of disease prevention. Under the principle of beneficence, individuals “have the responsibility to do good for others, to prevent harm to others, or, at the very least, to avoid directly harming others.”¹¹² Within partner notification, such responsibility encourages index patients to participate in notification when they are found to have an STD. Furthermore, such duties can be reinforced by a state’s police powers whereby a state has the inherent authority “to enact law and promulgate regulations to protect, preserve, and promote the health, safety, morals, and general welfare of the people.”¹¹³ Governments have the constitutional authority to implement partner notification programs,¹¹⁴ yet compelling patients to take part in mandatory partner notification could very well trample upon individual liberties and defeat the potential of partner notification systems by discouraging patients and their partners from seeking testing. Hence, partner notification remains a voluntary action on the part of index patients even when the choice not to participate may injure others and cut against some of the goals of public health.

There are also ethical obstacles that are present within distinct demographics where rates of HIV and STDs have become especially burdensome. Particularly salient in these populations are questions of justice given that partner notification may not necessarily take into consideration the respective needs of these groups. For example, a

¹¹² Nancy E. Kass & Andrea Carlson Gielen, *The Ethics of Contact Tracing Programs and Their Implications for Women*, 5 DUKE J. GENDER L. & POL’Y 89, 92 (1998) (citing Tom L. Beauchamp & LeRoy Walters, *Ethical Theory and Bioethics*, in CONTEMPORARY ISSUES IN BIOETHICS 1, 30 (Tom L. Beauchamp & LeRoy Walters eds., 4th ed. 1994).

¹¹³ LAWRENCE O. GOSTIN, PUBLIC HEALTH LAW: POWER, DUTY, RESTRAINT 48 (2000).

¹¹⁴ Gostin & Hodge, Jr., *supra* note 42, at 52.

partner's participation in partner notification might increase his susceptibility to domestic violence should he test positive for HIV or another STD and be in a potentially violent relationship.¹¹⁵ African American men have discussed their fears of incurring unintended consequences from engaging with public health entities to contact sexual partners about an STD. In one study of African American men and their reluctance to use partner notification, participants reported that engaging in partner notification could tarnish their character and standing in the community should they be seen by a familiar face at a public health clinic.¹¹⁶ A positive HIV or STD test for these men could also erode their presentation of their assumed (hetero)sexuality should the test results somehow become public.¹¹⁷

Along with the above ethical tensions exists the debate over the questionable effectiveness of partner notification given the limited amount of data that is available on this practice, and whether its presence in the public health arsenal provides value to the individuals, their partner(s), and the communities that utilize these programs. While there is a larger body of scholarly literature around partner notification, empirical studies of the effectiveness of partner notification are few and mixed in their conclusions, raising questions as to whether partner notification has been effective when it comes to reaching

¹¹⁵ Kass & Gielen, *supra* note 112, at 99 (“For the . . . proportion of women who are HIV-positive, . . . contact tracing can pose serious risks to their safety if a male partner becomes violent after being informed of the woman’s status. This fear of violence is a concern with contact tracing that appears to impact women disproportionately.”).

¹¹⁶ Bronwen Lichtenstein & Jane R. Schwebke, *Partner Notification Methods for African American Men Being Treated for Trichomoniasis: A Consideration of Main Men, Second Hitters, and Third Players*, 19 MED. ANTHROPOLOGY Q. 383, 389 (2005) (“The men in this group felt that partner notification would leave a permanent stain on their character.”).

¹¹⁷ *Id.* (“This exposure would not only be discrediting, but would disrupt presentations of self as heterosexual because African Americans in the local community associated STI infections with homosexuality.”).

potentially exposed partners and decreasing the presence of HIV and other STDs. Because the scientific data from this small pool of studies on the effectiveness of partner notification is central to discussing its ethical undertaking through the lens of the Kass framework, only those studies will be discussed herein.

b. An Ethical Framework for Analyzing Online Partner Notification

Online partner notification faces the very same dilemmas as conventional partner notification, which historically has been conducted offline. The transference of this public health tool from the clinic office and face-to-face communication to websites and emails does not free it from the ethical principles that guide and also constrain its application to disease control. Threats to privacy, confidentiality, autonomy, and justice are very real in online partner notification. The placement of partner notification in a digital environment could be cause for alarm or reason to take comfort. The online world brings with it rapid speed and a reach that is incomparable to offline notification avenues for contacting partners. But it can also be much easier to diffuse sensitive information to unintended parties or to decipher the identity of an index patient despite the intentionally anonymous or confidential nature of a partner notification message. Despite the importance of the move of partner notification to the online environment, there is no ethical analysis of online partner notification in the bioethics or public health literature, and what is presented here is intended to help begin filling that void. To address this gap, this thesis is the first ethical analysis of online partner notification, and the first direct comparison of offline and online partner notification methods.

In order to identify and analyze the numerous ethical issues presented by online partner notification and offline partner notification, and the competing interests therein, this Part will apply the ethical framework for public health envisioned by Nancy Kass.¹¹⁸ The Kass framework is appropriate for this investigation because it provides a pragmatic analytical tool that bridges the practical issues faced by public health practitioners with the ethical considerations that must underlie the implementation of every public health intervention.¹¹⁹ This is distinct from other frameworks of public health ethics which can be considered less rigorous in their approaches, such as the model provided by Childress et al. which calls for a broader evaluation of “general moral considerations,”¹²⁰ or the framework forwarded by Gaare Bernheim, Nieburg, and Bonnie that uses a list of general questions for “identifying and recognizing ethical issues and considerations”¹²¹ in public health. The Kass framework operationalizes the ethical inquiry, allowing for one to ascertain the ethical implications of a specific policy or program, incorporating the moral and ethical considerations other ethicists have outlined as imperative to public health actions, including effectiveness, proportionality, necessity, the infringement of rights, and the justification for a program’s use.¹²² This exploration will look at how each form of partner notification—online and offline—aligns with, and differs from, the other, and what these similarities and distinctions mean for the entities and individuals engaged in

¹¹⁸ Nancy E. Kass, *An Ethics Framework for Public Health*, 91 AM. J. PUB. HEALTH 1776 (2001).

¹¹⁹ *Id.* at 1777.

¹²⁰ James F. Childress et al., *Public Health Ethics: Mapping the Terrain*, 30 J.L. MED. & ETHICS 169 (2002).

¹²¹ Ruth Gaare Bernheim, Phillip Nieburg & Richard J. Bonnie, *Ethics and the Practice of Public Health*, in *LAW IN PUBLIC HEALTH PRACTICE* 110–25 (Richard E. Hoffman et al. eds., 2d ed. 2007).

¹²² *See, e.g.*, Childress et al., *supra* note 120, at 171–72.

partner notification, as well as their impact on public health. Kass states that while the fundamental principles of bioethics are clearly relevant to public health, the analytical frameworks and ethical codes that have been derived from these principles for their use in medicine and clinical research are not necessarily an appropriate fit for public health practice.¹²³ Because of the manner in which some public health programs and actions are created—often through the enactment of federal and state regulations and legislation—these attempts to decrease morbidity and mortality raise ethical questions about just how to balance state action with individual rights in order to attain success on the public health front through partner notification.¹²⁴ Therefore, Kass argues that a particular framework is necessary for assessing public health actions, one that can “preserve fairly and appropriately the negative rights of citizens to noninterference” and that must “emphasize positive rights as well”¹²⁵

Under the ethics framework for public health, a program is assessed according to six distinct questions: 1) What are the public health goals of the proposed program? 2) How effective is the program in achieving its stated goal? 3) What are the known or potential burdens of the program? 4) Can the burdens be minimized? Are there alternative approaches? 5) Is the program implemented fairly? 6) How can the benefits and burdens of a program be fairly balanced?¹²⁶ In their application to online and offline partner notification, each question will be scrutinized carefully using the independent research conducted for this thesis in concert with the relevant literature on public health

¹²³ Kass, *supra* note 118, at 1777.

¹²⁴ *Id.* at 1776–77.

¹²⁵ *Id.* at 1777.

¹²⁶ *Id.* at 1777–81.

ethics and epidemiological research on all forms of partner notification in the United States, with particular attention given to studies that have focused on the use of partner notification for HIV/STD prevention in gay men.

c. Applying the Kass Public Health Ethics Framework

i. Question One: What Are the Public Health Goals of the Proposed Program?

1. The Goals of Partner Notification

The first step in applying an ethical framework to the practice of partner notification is to identify the goals of this public health strategy. As Kass notes, because public health is unique in its population-based focus (as opposed to the individualized focus of medicine), these goals ought to be framed in terms of a reduction in morbidity and mortality.¹²⁷ The overarching goal of partner notification programs, both online and offline, is two-fold. First, at the individual level, the goal of partner notification is to inform an index patient's sexual partner(s) about their possible risk of exposure to HIV or an STD, so that those individual(s) can be directed to testing and, if necessary, medical treatment.¹²⁸ The second goal of partner notification is at the population level, and that is to locate undiagnosed and untreated cases of HIV/STDs in order to decrease transmission rates and the HIV/STD burden in the population.¹²⁹ Although the Kass framework is primarily focused on overarching public health goals, it is a useful device for considering individual outcomes along with those population-based implications because partner

¹²⁷ *Id.* at 1777.

¹²⁸ CDC, *HIV, Hepatitis, STD and TB Partners* (Dec. 1, 2011), <http://www.cdc.gov/nchstp/partners/faq-public.html>.

¹²⁹ *Id.*

notification is itself an intervention that operates on several levels. Whether the means of undertaking partner notification are phone calls, e-cards, or text messaging services, the end goals are to warn individual sexual partners of the health risks to which they have been exposed, and, in terms of epidemiological outcomes, to reduce HIV/STD transmission throughout the general public; however, the goals of this disease tracing method do not end there.

Also relevant to this analysis is an understanding of to whom the benefit will accrue.¹³⁰ “Public health interventions often are targeted to one set of individuals to protect *other* citizens’ health.”¹³¹ In partner notification, the intervention is directed at two specific groups of individuals: the index patients and their partners. For index patients, the benefits of partner notification can include receiving assistance from disease investigators in notifying partners of their possible exposure to an infection, as well as having the opportunity to access medical care, other HIV/STD prevention services, and if necessary social services such as substance abuse treatment.¹³² The benefits for partners come from being notified about their potential exposure to HIV or an STD, and then being referred to testing, and if needed, treatment, along with other social services should those be appropriate.¹³³ When taken together, the benefits accrued for both index patients and their sexual partners are conceptualized to improve the overall health of the public by identifying possible routes of disease transmission, testing those who may have been exposed, and then treating the people who have been infected.

¹³⁰ Kass, *supra* note 118, at 1778.

¹³¹ *Id.*

¹³² CDC, *supra* note 128.

¹³³ *Id.*

ii. Question Two: How Effective is the Program in Achieving its Stated Goals?

The next step of analysis necessitates that the effectiveness of the public health program be evaluated. As a public health intervention, partner notification is meant to work as follows: index patients, who are diagnosed with HIV or another STD, will use partner notification to notify their sexual partners about a potential exposure, which in turn will lead to the identification and treatment of new infections and stop the further spread of disease. There are two goals for partner notification. For individuals, the goal is to use partner notification to warn sexual partners about their risk of exposure so that the partners can seek out testing and treatment if necessary. The population-level goal is to reduce the prevalence and incidence of HIV and STDs in the population, thereby reducing morbidity and mortality related to HIV/STDs. To ascertain the effectiveness of partner notification in actually fulfilling those assumptions, the existing literature on offline partner notification and online partner notification must be reviewed.

1. Offline Partner Notification

Offline partner notification, as a strategy for combating HIV and STD transmission, is a relevant public health intervention. However, the effectiveness of offline partner notification in working with index patients and establishing contact with partners has been suboptimal to the extent of what can be measured.¹³⁴ Reviews of the effectiveness of partner notification are few and mixed in their conclusions, raising

¹³⁴ See E. Jennifer Edelman, et al., *Opportunities for Improving Partner Notification for HIV: Results from a Community-Based Participatory Research Study*, AIDS & BEHAV. (2014) (available electronically ahead of print) (“Despite its relevance for curbing the HIV epidemic, disclosure practices and the implementation of PN for HIV among MSM are suboptimal.”).

questions as to whether partner notification has been effective when it comes to reaching potentially exposed partners and decreasing the presence of HIV and other STDs. Part of this problem is definitional. What do we measure and how are we measuring it? If the unit of measurement is a reduction of STD rates because of partner notification efforts, the ways in which to assess such effectiveness become incredibly complex.¹³⁵ While partner notification has been shown to be helpful in curtailing localized outbreaks of bacterial STDs,¹³⁶ its utility on a larger scale for effectively reaching sexual partners and reducing disease incidence is open to debate.¹³⁷ The efficacy of partner notification presents reasonable questions for public health given the time, energy, and resources invested into this endeavor across states and communities.

Evaluations of the effectiveness of partner notification programs across the United States have found outcomes that have not met the expectations of public health practitioners in terms of their utility in reaching sexual partners and in identifying new cases of disease in those partners that are screened. For example, in a 2003 study that examined syphilis partner notification efforts in eight U.S. cities, 1,517 index patients reported a total of 10,254 sex partners, but only 1,579 of these partners were contacted,

¹³⁵ Gostin & Hodge, *supra* note 42, at 73 (“Examining the scientific efficacy of partner notification is not a simple task. Efficacy is largely an empirical question. Measuring the effectiveness of partner notification through contact tracing is problematic. No scientifically valid empirical standard exists to measure the effectiveness of contact tracing as applied to STDs across large populations.”).

¹³⁶ See, e.g., Katrin S. Kohl et al., *Usefulness of Partner Notification for Syphilis Control*, 26 SEXUALLY TRANSMITTED DISEASES 201 (1999) (discussing the beneficial aspects of using partner notification to identify and contact individual exposed to syphilis in Louisiana between 1993 and 1996).

¹³⁷ M. Hogben et al., *Syphilis Partner Notification With Men Who Have Sex With Men: A Review and Commentary*, 32 SEXUALLY TRANSMITTED DISEASES S43, S44 (2005).

representing a median of fourteen percent of partners successfully contacted.¹³⁸ Such findings are not completely unexpected as this has been largely the case for much of partner notification's history in the United States, where many scholars have commented on the limited effectiveness of partner notification to reduce transmission,¹³⁹ with others stating that too little is known about its public health effectiveness.¹⁴⁰ Similar conclusions have been made about its effectiveness in international contexts as well.¹⁴¹

Several studies of partner notification have examined why it is not a more effective public health practice. Research has found that index patients cannot accurately identify past sexual partners when the sexual encounter has been anonymous, while other index patients may be unwilling to cooperate with disease investigators because of their distrust of public health departments.¹⁴² Quantifying partner notification effectiveness may be limited. If partner notification is being geared towards populations that have higher levels of anonymous sexual encounters, initiated in communities that have displayed a distrust in public health, or both, then it will surely be difficult to achieve the desired effectiveness outcomes that other public health interventions may more easily

¹³⁸ *Id.*

¹³⁹ Bayer & Toomey, *supra* note 50, at 1159 (quoting June Osborn, the then-Dean of the University of Michigan School of Public Health and the then-chair of the National Commission on AIDS, who said "As to mandatory tracing of the sexual partners of persons with AIDS, the justification offered is that it is a tried and true method of controlling STD, but in fact it has never worked well").

¹⁴⁰ See, e.g., Allan M. Brandt, Editorial, *Sexually Transmitted Disease: Shadow on the Land, Revisited*, 112 ANNALS INTERNAL MED. 481, 481 (1990) ("Do partner notification programs achieve their goals? It is striking how little is known about the relative cost and effectiveness of these programs.").

¹⁴¹ See, e.g., Fleur van Aar et al., *Current practices of partner notification among MSM with HIV, gonorrhoea and syphilis in the Netherlands: an urgent need for improvement*, 12 BMC INFECTIOUS DISEASES 1 (2012) (discussing how partner notification efforts for MSM in the Netherlands are suboptimal because an extensive number HIV and STD infections went undetected in one particular study).

¹⁴² Hogben et al, *supra* note 138, at S44.

obtain. Other studies have reported that index patients may experience embarrassment, shame, guilt, or fear rejection from current partners, while still others may feel a minimal responsibility or obligation to notify because “choosing to engage in risky sexual behavior involves an inherent risk of spreading infection.”¹⁴³ Once again, the limitations on determining effectiveness may have little to do with the strategy and methods of partner notification itself, but may simply be constrained by human nature. In order to arrive at a more realistic idea of what “effectiveness” means within partner notification, focusing on these obstacles and the specific populations that present them will be necessary in future work.

2. Online Partner Notification

When compared to offline partner notification, online partner notification has received considerably less attention because it is relatively new in its use in the field. And just as the review of offline studies above demonstrate, the small amounts of data that exists on online partner notification raises similar questions about its effectiveness. In a 2005 observational assessment of the use of an online partner notification program in Denver by a predominately urban heterosexual population, researchers found no effectiveness in terms of usage of the site despite in-person (e.g., in the clinic) and web-based interventions to promote its use. Despite promotion of the partner notification site online, in person, and through other media outlets (e.g., radio announcements), of the 481 patients surveyed, only twenty-eight had ever heard of the site, only ten had ever used the site to send a notification message (with only three of the ten respondents correctly

¹⁴³ See Matthew J. Mimiaga, et al., *Partner notification after STD and HIV exposures and infections: knowledge, attitudes, and experiences of Massachusetts men who have sex with men*, 124 PUB. HEALTH REP. 111 (2009).

identifying the purpose of the message), and only five having ever received a message. When patients were asked how they would prefer to notify partners if diagnosed with an STD, eighty-nine percent said they would do so in person and thirty-seven percent said they would do so by phone. Only 4.8% said they would use email to notify partners, and eleven percent said they would use text messaging. Although online banner ads and other promotional activities appear to have increased interest in the site, use of the site was not sustained despite continued marketing activities. Of the notification messages that were sent in one year (1,885), a disproportionate amount (537) were sent out regarding exposure to scabies and pubic lice, which are conditions rarely seen in HIV/STD clinics and are also non-reportable. The authors of this study suggest that these messages may be evidence of inappropriate use of the notification site.¹⁴⁴

A small randomized controlled trial examining the use of patient-delivered partner therapy and online partner notification among MSM with gonorrhea or chlamydia found equally little appeal for online partner notification, with men choosing overwhelmingly not to use the site to contact sexual partners.¹⁴⁵ In a separate study by the researchers of the randomized controlled trial, 182 MSM were surveyed in 2013 about the acceptability

¹⁴⁴ Cornelis A. Rietmeijer, et al., *Evaluation on an Online Partner Notification Program*, 38 SEXUALLY TRANSMITTED DISEASES 359, 362 (2011) (“The clinic-based evaluation demonstrated low base- line use and no apparent effect of a reasonable intervention to enhance the use of the site that could be implemented in real-world settings. Also, web-based efforts, while increasing site use, did not result in higher recognition or use rates by clinic patients.”).

¹⁴⁵ Roxanne Pieper Kerani, et al., *A randomized, controlled trial of inSPOT and patient-delivered partner therapy for gonorrhea and chlamydial infection among men who have sex with men*, 38 SEXUALLY TRANSMITTED DISEASES 941, 944 (2011) (“We found that virtually no MSM wanted to use inSPOT, even though using e-mail to notify partners was common.”).

of, and their intention to use, online partner notification.¹⁴⁶ Both positive and negative effects for HIV/STD prevention and treatment were found. Thirty-nine percent of MSM reported being interested in using online partner notification to anonymously contact partners, and forty-five percent felt that having the option to utilize online partner notification would make them more likely to notify partners.¹⁴⁷ However, men indicated that they were less likely to seek care, such as HIV/STD testing, and less likely to notify their other partners in the event they received an anonymous e-card versus another form of notification such as by telephone or an in-person discussion.¹⁴⁸ Most men reported that instead of using an e-card, they would prefer to notify partners in person (fifty-three percent) or by phone (sixty-two percent).¹⁴⁹ Only thirty-nine percent stated that they would use the e-card option.¹⁵⁰

These findings conflict with a 2008 study of the opinions of 1,848 MSM recruited nationally on the acceptability of using online partner notification, which found that seventy percent of men would be open to contacting partners via an online notification system.¹⁵¹ It's important to note, however, that this 2008 study was conducted through the recruitment of MSM via an online hookup site who were asked about their opinions on online partner notification and their intent to use these systems via an online survey,

¹⁴⁶ Roxanne Pieper Kerani, Mark Fleming & Matthew Robert Golden, *Acceptability and Intention to Seek Medical Care After Hypothetical Receipt of Patient-Delivered Partner Therapy or Electronic Partner Notification Postcards Among Men Who Have Sex With Men: The Partner's Perspective*, 40 SEXUALLY TRANSMITTED DISEASES 179, 183 (2013).

¹⁴⁷ *Id.* at 183.

¹⁴⁸ *Id.*

¹⁴⁹ *Id.*

¹⁵⁰ *Id.*

¹⁵¹ Matthew J. Mimiaga, et al., *Acceptability of an internet-based partner notification system for sexually transmitted infection exposure among men who have sex with men*, 98 AM. J. PUB. HEALTH 1009, 1010 (2008).

while the 2013 study recruited men through STD clinics and private medical practices and surveyed them in person, where the reality of actually having to engage in partner notification may be more tangible.

Taken altogether, these examinations into the use and acceptability of online partner notification reveal just how much is unknown about the potential for using this public health instrument. One study utilized a sample population that has seldom been the focus of online disease prevention methods (e.g., heterosexuals) and promoted online partner notification through offline means such as radio announcements and clinic postings. Yet those studies that have focused on MSM have found greater acceptability and enthusiasm for online partner notification, particularly when compared with the pursuit and success of offline partner notification methods, and shown that there may exist a real possibility for the greater use of online partner notification than the notification systems of the past. As Kass states, the public health intervention must be “reasonably likely to achieve its stated goals”,¹⁵² and for online partner notification, it may be able to achieve the dual goals of partner notification both at the individual level and at the population level. In order to arrive at a more decisive statement about the effectiveness of online partner notification, more research is simply needed, including research that examines the combined effectiveness of online and offline partner notification when pursued in concert with one another as complimentary strategies of intervention.

¹⁵² Kass, *supra* note 118, at 1779.

iii. Question Three: What are the Known or Potential Burdens of the Program?

The third step of this ethical framework requires an identification of the known or potential burdens of the program in question. While there are a variety of burdens that can come with any public health program or intervention, Kass states that the majority of these burdens fall into three categories: risks to privacy and confidentiality, risks to liberty and self-determination, and risks to justice.¹⁵³ Risks to privacy and confidentiality are particularly relevant if the activity in question deals with data collection or the handling of highly sensitive information.¹⁵⁴ Challenges to one's liberty and self-determination often stem from the very powers that define public health: the inherent powers of the state to enact whatever measures may be necessary to contain and prevent the transmission of disease.¹⁵⁵ Threats to justice are often the result of public health actions that target a specific group rather than being directed at the general population.¹⁵⁶ All three burden categories will be analyzed below, starting with the burdens imposed by traditional offline partner notification, and then moving to those burdens that may be present within online partner notification.

1. Offline Partner notification

a. Privacy and Confidentiality

In offline partner notification, the burdens that are present impact both the index patient and their sexual partners given the delicate nature of partner notification in

¹⁵³ Kass, *supra* note 118, at 1779.

¹⁵⁴ *Id.*

¹⁵⁵ *Id.*

¹⁵⁶ *Id.*

collecting a sexual history and disease status from the index patient, and then using this information to anonymously or confidentially notify partners. The risks to the index patient's and the partner's privacy interests are salient throughout the partner notification process. Beginning with the index patient, partner notification requires that the patient's informational and associational privacy be, to some degree, eroded in order for the notification process to commence. Informational privacy pertains to the ability of the index patient to protect the unique and identifiable information about himself, including exerting control over who can have access to this information.¹⁵⁷ Within partner notification, this means the patient's protection and control over their disease diagnosis, their medical history, as well as any other piece of deeply personal or identifying information. Associational privacy, as conceived by Beauchamp and Childress, focuses on the intimate relations "within which individuals make decisions in conjunction with others," including lovers and spouses.¹⁵⁸ This form of privacy is relevant given that index patients must discuss their sexual histories, including the names and contact information of their partners, the sexual acts they engaged in with those partners, and whether any form of prophylaxis was used. Because these pieces of information must be shared in some way in order for disease investigators to assist or guide patients through the partner notification process, the informational and associational privacy of the patient is infringed in order to facilitate notification, yet just how heavy that burden is depends on the individual given that participation in partner notification is entirely voluntary. For those

¹⁵⁷ Anita L. Allen, *An Ethical Duty to Protect One's Own Informational Privacy?*, 64 ALA. L. REV. 845 (2013).

¹⁵⁸ TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 312 (7th ed. 2013).

patients who hold privacy dear and safeguard it at all costs, the burden of partner notification will be substantial, and likely create great discomfort regardless of the good that will come from warning partners about a possible exposure. And for the index patient who is not shy about discussing the intimate details of his health status and sexual history, the infringements upon his informational and associational privacy will be considerably less than those who are more guarded.

The burdens faced by sexual partners also include an infringement upon the person's informational and associational privacy; however, for partners, they have less autonomous control over these burdens given how partner notification is conducted. Index patients voluntarily engage in partner notification by sharing their disease statuses and sexual histories with public health and the partners they contact, but partners have no such say. Their privacy is intruded upon when their names, contact information, and other personal details are handed over to disease investigators, or when index patients take action to identify partners who have been potentially exposed. If and when partners are contacted, they must deal with the fact that their identities and portions of their sexual lives have, to a limited extent, been revealed.

Risks to the confidentiality of index patients and sexual partners are also present in offline partner notification. These burdens are dependent on how the notification is made and who may intercept the notification message. Once an index patient has been informed of his HIV/STD status, the potential for confidentiality to be breached grows once they volunteer information about their personal health, their sexual history, and the identities and contact information of their partners. The more partners that must be

contacted, the more information that must be exchanged, and the greater the likelihood that persons outside the patient-partner relationship will learn about something related to the notification. Phone calls or voicemails may be intercepted by spouses, partners, or significant others, and face-to-face conversations could be overheard by friends or strangers depending on the location and context of the discussion. Great care is taken (and legally required) by disease investigators and other public health personnel to prevent lapses in confidentiality and to prevent highly personal information from falling into the wrong hands. An unwarranted breach of confidentiality could result in social stigma, emotional or physical harm to the index patient or the partner, and trust in public health could be undermined, creating devastating consequences to future partner notification efforts.

b. Liberty and Self Determination

In offline partner notification, the burdens to the index patient's liberty and self-determination are low. In the sexual situations that are under consideration in this thesis, partner notification is a voluntary practice, where patients who are diagnosed with HIV or an STD are strongly encouraged to take part in partner notification. But in the end, participation is ultimately a decision that is left in the hands of the patient. It is, however, the legal and ethical duty of public health officials to ensure that the index patient's final determination is one that is informed and thoroughly considered. Public health departments have a positive obligation to respect the autonomy of index patients, meaning public health workers are required to "disclose information, to probe for and

ensure understanding and voluntariness, and to foster adequate decision making.”¹⁵⁹ Public health programs must give due diligence to telling index patients about the risks and benefits of notifying partners, including the potential harms of losing some privacy and confidentiality or the consequences of not contacting sexual partners, so that the liberty of patients is not hindered. Once patients have the knowledge necessary to make an autonomous decision that is right for them, threats to the liberty and self-determination of the index patient should be of little concern going forward.

Challenges to a partner’s liberty and self-determination are more pronounced than those of an index patient. A partner has no choice as to whether he wants to participate in partner notification. He is contacted and told of his possible exposure with no real opportunity to decline receiving this information other than refusing to answer a notification phone call or declining to discuss the content of the notification with the patient or disease investigator. Should the partner choose to receive his contact, what is done with this newfound information is entirely up to him, of course. This burden to a partner’s liberty is unavoidable. While an index patient could possibly alleviate some of this weight by considering which partners will or will not want to be contacted about their risk of exposure, such preferences may be unknown to the patient, or what the patient believes to be the partner’s preference could be quite the opposite. A patient may not be pleased to become involved in the partner notification process and find it an infringement into how he lives his life and the choices he makes about his health, but it is more often than not a burden he will have to experience in a process that is designed to ultimately better protect his health.

¹⁵⁹ *Id.* at 107.

The different types of information being exchanged and the different parties with whom that information is being shared have varying implications for the partner, as well. When an index patient and his sexual partner have unsafe sex, both of them might be already aware that they have engaged in risky behavior, and therefore, the knowledge and recognition of this act is not burdensome to either individual. It is worth noting that this may not be entirely true in all scenarios, however, given how much misinformation can be communicated (or not) during a sexual encounter, and just how poor many are at quantifying the riskiness of their sexual health risk behavior, meaning a heavier burden may be shouldered by some more than others depending entirely on the facts of the situation.

The notification message from the index patient carries with it a heavier burden. Instead of simply carrying on with life without a second thought about the ramifications of a past sexual experience, the partner is now confronted with the realization that the index patient has an STD, and the partner now has to face the realistic possibility that he himself may have been exposed. The degree of burden depends on several factors. Did the sexual partner know beforehand that the index patient might already have an STD? Has the partner recently been tested for STDs and is he already aware of an existing infection or lack thereof? What is the STD in question, and how serious is the health issue before him? These different scenarios can shift the significance of the burden, meaning that the notification may come as no surprise, or it may reveal a troubling health issue that the partner was not prepared for and may have difficulty in determining the next best step for himself. What must also be factored in are situations where additional

harms may transpire. For example, an index patient and his sexual partner may have an unhealthy relationship where one or both individuals do not remain in contact, or where the threat of personal safety to the index patient or the partner may be a possible consequence from reestablishing communication via partner notification. A patient's trustworthiness may also be called into question. If a patient tells his partner that he is HIV-negative yet it is later revealed that he is positive, a serious breach of trust can fracture their relationship, the partner's ability to trust future sexual partners, or both.

Finally, there is the burden a partner can face in seeking out testing, and then having to deal with the results of those tests. As is noted, the severity of the diseases in question could weigh heavily upon an individual. For illnesses such as gonorrhea or chlamydia, the treatment of the disease is simple. This, of course, does not mean that the experience of a being exposed to a curable STD will not engender stigma, shame, or a sense of vulnerability, as can often be the case with any STD. An HIV-positive diagnosis can be devastating news to handle on the other hand, and the revelation of such information is regularly cited as to why more people do not seek out HIV testing.¹⁶⁰ The burden an HIV-positive test result can bring is often tremendous, and when delivered to an unsuspecting partner, perhaps even more so. Now not only does a partner have to deal with the burden of having this new and possibly unwanted knowledge about his health,

¹⁶⁰ See, e.g., CDC, *HIV prevalence, unrecognized infection, and HIV testing among men who have sex with men – five U.S. cities, June 2004-April 2005*, 54 MORBIDITY & MORTALITY WKLY. REP. 597 (2005); Heather A. Joseph et al., “*The anticipation alone could kill you*”: *Past and potential clients’ perspectives on HIV testing in non-health care settings*, 23 AIDS EDUC. PREVENTION 577 (2011); Duncan A. MacKellar et al., *Reasons for not HIV testing, testing intentions, and potential use of an over-the-counter rapid HIV test in an internet sample of men who have sex with men who have never tested for HIV*, 38 SEXUALLY TRANSMITTED DISEASES 419 (2011).

he must now decide how to negotiate his future steps in life, and just how privately he wants to hold this detail of his personal health.

c. Justice

Justice “requires that people are treated fairly; restrictions cannot be imposed on, or benefits provided to, one person or one group of people when another similarly-situated person or group is treated differently without adequate justification.”¹⁶¹ Burdens to justice within the realm of partner notification would arise if this tool were only used for gay men or African Americans. For instance, early research on partner notification found that some physicians were more likely to break confidentiality based on an HIV-positive patient’s gender, race, and sexual orientation.¹⁶² Such reprehensible actions during the 1980s and early 1990s were clearly unjust, and their continued practice in the present day would certainly be cause for alarm. In general, however, partner notification is not intended nor designed to be applied in such discriminatory ways. It is to be implemented in all communities, and made available to all index patients and sexual partners regardless of individual or community characteristics. While offline partner notification is certainly more likely to be a disease prevention tool that is used within some demographics more than others, these differences can be attributed to HIV/STD burdens within those communities where the incidence and prevalence of HIV and other STDs are disproportionate. Partner notification should not be manipulated to serve or disserve particular patients or particular partners, but should be utilized to assist those who

¹⁶¹ Kass & Gielen, *supra* note 112, at 98.

¹⁶² See Judith A. Schwartzbaum, John R. Wheat & Robert W. Norton, *Physician Breach of Patient Confidentiality among Individuals with Human Immunodeficiency Virus (HIV) Infection: Patterns of Decision*, 80 AM. J. PUB. HEALTH 829 (1990).

are infected with an STD or HIV in order to warn others about their health risks regardless of who they are and how they may have been exposed.

2. Online Partner Notification

a. Privacy and Confidentiality

Concerns over the infringement of privacy and confidentiality are equally felt within the online context just as they are offline given the personal, sexual, and health information being exchanged between clinics, public health workers, patients, and partners. For index patients, the core concerns remain the same in using online partner notification because using online tools to communicate to partners about their HIV/STD status requires patients to relinquish some of their informational and associational privacy. Patients may have to divulge the same information in online partner notification that they would in offline partner notification, and the only difference may be the medium.

The same holds true for partners. As with offline partner notification, online partner notification means that some details of their lives will become known to all involved in the process. And just like traditional partner notification, partners who are contacted via online notifications have little say on how the process is carried out and who knows about their private information until they actually receive the notification message.

The two different online partner notification systems discussed here both have aspects to their operations which could reduce the burdens to privacy already at play in the notification. Both partner notification programs require less identifiable information

to be used simply because very limited personal information is needed to make a notification contact. Users of Manhunt's partner notification system only require the username/handle of the sexual partner in order to send them a notification message. An index patient does not have to supply the names of his sexual partners, nor does he have to supply their contact information, and the patient himself can request that the message be entirely anonymous. Therefore, the partner notification system for Manhunt allows both patients and partners to reveal less private information than is needed to initiate the notification process offline. The partner notification system of inSPOT allows privacy to be guarded in a different manner. Its partner notification system can be entirely patient driven, which means the index patient does not have to divulge his entire sexual history nor provide public health with any identifying information about his sexual partners. The only communication that transpires can be entirely between the patient and his partners, limiting the intrusion into the privacy of all parties involved in the notification process.

It is also worth noting that there may exist a privacy concern for users of Manhunt's partner notification system in that it is staffed and housed within the larger umbrella of a company that caters to gay men and is used for a collection of sexual and community purposes. While Manhunt's partner notification messages are initiated by diseases investigators who have access to the notification site, and who do so with the assistance of the index patient, it is possible that index patients could be hesitant to use the very same site where they have met sexual partners to re-contact partners regarding a serious matter such as an HIV/STD diagnosis. Online Buddies employees do not have access to the partner notification messages that are sent, and as was noted earlier, the

partner notification service is entirely separate from the company's other services; however, an index patient may be unwilling to utilize Manhunt's partner notification service for fear of being "found out" by company employees, or that somehow this information could be leaked to other hookup site users. Although such fears would be unfounded given the technical construction of the partner notification site, any cause for hesitation or concern could deter index patients from utilizing the full capabilities of the site to notify partners of their possible risk. In addition, the index patient may simply have a negative attitude and internal distrust of gay men, and then bypass Manhunt's partner notification services because of these beliefs and perceptions. Finally, a patient or partner who becomes infected with an STD from meeting someone on Manhunt's hookup site may experience a sense of injury or anguish from having been exposed to an STD via the site, and would avoid using Manhunt's partner notification system altogether to avoid revisiting the website that he now associates with a painful life episode.

Separate from privacy, the burdens to confidentiality for index patients and partners are still present. Just like offline notification, the possibility of information being revealed to others outside the notification process certainly remains. An anonymous notification message sent online does not eliminate the chance that another person, who is neither the patient nor a partner, will learn about the notification message and its content. But the potential for breach, no matter how unlikely, still remains with any type of online activity notwithstanding steps taken to guard against infractions.

Both inSPOT and Manhunt have put into place privacy and confidentiality protections to better shield the partner notification process from prying eyes. When an

anonymous notification message is sent, inSPOT does not collect any information that can be shared, forwarded, or sold to a third party, and no information is available to be used by inSPOT's administration.¹⁶³ InSPOT informs users that it does not collect the addresses anywhere, and the organization does not possess a backend database for its partner notification services.¹⁶⁴ The only exception to this policy on divulging personal information is that inSPOT will release information if the organization is "asked to comply with any valid legal process such as a search warrant, subpoena, statute or court order."¹⁶⁵ Separate from the messages themselves, inSPOT makes it known that it uses de-identified aggregate information such as the number of e-cards sent each month or number of e-card recipients for improving the administration and usability of its sites, or for data that is used in journal articles, conference presentations, and informational workshops.¹⁶⁶

Although the partner notification system operated by Online Buddies is only for Manhunt members, the partner notification system has several protections in place as well. First, and perhaps most importantly, the entire Manhunt partner notification service is completely separate from the hookup services that are provided by Online Buddies.¹⁶⁷ All partner notification messages are created, contained, and sent from a dedicated server that is in no way connected to any information on the user's Manhunt account.¹⁶⁸ All

¹⁶³ *Community Guidelines*, INSPOT.ORG, <http://inspot.org/Confidentiality/tabid/67/language/en-US/Default.aspx> (last visited July 13, 2014).

¹⁶⁴ *Id.*

¹⁶⁵ *Id.*

¹⁶⁶ *Id.*

¹⁶⁷ Interview with David S. Novak, Senior Public Health Strategist, Online Buddies, Inc., in Cambridge, Mass. (Aug. 2010).

¹⁶⁸ *Id.*

partner notifications are stored on this one server, and then erased every month.¹⁶⁹ Like inSPOT, the only data that are collected are the number of messages that are sent from the service, as well as the number of message recipients.¹⁷⁰ Different from inSPOT, partner notification messages cannot be sent from a user's Manhunt messaging system (akin to personal email) and does not contain any personal information except for the name of the confirmed illness. Manhunt members are actually unable to initiate designated partner notification messages from their accounts, and as noted earlier, messages can only be created and sent by staff from partnering STD clinics and outreach organizations.

b. Liberty and Self-Determination

The ability of index patients to make informed and autonomous decisions about participating in partner notification is equally as necessary in the online world as it is offline, meaning it is important that index patients comprehend the totality of benefits and burdens online partner notification presents before taking part in this system. Similarly, the burdens faced by partners receiving possibly unexpected online notification messages are like those present in offline notification. Once again, partners will have little say in receiving a notification, and thus, find themselves in the notification process where they will have to decide how to best proceed in light of the health information given to them.

The two systems under examination here do not further burden the liberty interests of patients and partners. Manhunt's notification system operates just like an offline clinic-based notification system where the disease investigator initiates

¹⁶⁹ *Id.*

¹⁷⁰ *Id.*

notification and index patients who are members of the Manhunt hookup site can utilize these services free of charge. Because of the aid of a disease investigator, having information and assistance on hand to promote his informed choices can bolster a patient's autonomy. Similarly, inSPOT places the responsibility in the hands of the index patient, or, depending on the clinic, allows a disease investigator to guide the patient through the partner notification process. Should a patient decide to undertake notification on his own, it is the patient who determines how the notification process will commence, thereby enhancing his autonomy by giving the patient control over who will be contacted, how the message will be crafted, and just when the message(s) will be sent. Again, even though partner notification is entirely voluntary, a patient may feel more empowered using the inSPOT site because it fully allows him the flexibility to shape the partner notification experience around his own needs rather than those of a public health department. Whatever form of notification the patient chooses to use, the opportunity for greater liberty and self-determination is available.

c. Justice

Concerns about justice in online partner notification carry little weight. These systems are not being created to disparately target one population over another, and like the example of inSPOT shows, notification systems are being built to service all members of the general public regardless of gender, race, class, and sexual orientation. Manhunt's system is closed in that only members of the Manhunt hookup site can utilize its partner notification system. But this does not adversely impact those outside of this self-selecting community because they will have not used the hookup site to find potential sexual

partners. Finally, it could be argued that online notification systems only cater to those who are technologically literate and have full access to the online world, but because online partner notification can be used as a compliment or alternative to offline methods, offline partner notification remains a viable option to those outside the digital sphere.

iv. Question Four: Can Burdens be Minimized? Are there Alternative Approaches?

The fourth step of the Kass framework requires that once the burdens of the public health intervention are identified, it is ethically required to “determine whether the program could be modified in ways that minimize the burdens while not greatly reducing the program’s efficacy.”¹⁷¹ This does not require that all measures that can be possibly imagined be taken to reduce these burdens, but that the program has in place means to implement ethically sound practices that fairly and effectively limit the exposure of participants to harm. What is interesting about this step with regard to partner notification is that in some ways, online partner notification has developed as a way to respond to the deficiencies of traditional offline notification methods. For example, offline partner notification has often been viewed as resource intensive and inefficient,¹⁷² and online partner notification systems have sought to alleviate those obstacles. In order to analyze whether the burdens of offline partner notification have been lessened by online partner notification, both will be discussed side by side.

¹⁷¹ Kass, *supra* note 118, at 1780.

¹⁷² See, e.g., Mary D. Fan, *Sex, Privacy and Public Health in a Casual Encounters Culture*, 45 U.C. DAVIS L. REV. 531, 566 (2011) (“In our contemporary era of strained state budgets and cuts to public health funding, contact tracing is proving particularly cumbersome, costly, and spotty.”).

1. Privacy and Confidentiality

Threats to privacy and confidentiality are at the heart of partner notification, whether the intervention is conducted online or offline. The possibility that these burdens will ever be fully eliminated is unlikely given that this form of disease tracing and prevention strikes at the most private dimensions of a person's life. Offline partner notification methods have sought to minimize these inherent burdens, and online partner notification has followed these efforts.

First, because partner notification is voluntary, public health workers are required to inform index patients that they have a right to decline participation, and should they decide to take part in partner notification, they must be informed that the notifications can be done confidentially or anonymously, and that the notification messages can be delivered by a disease investigator, the patient, or by both such as in the case of conditional referral. Second, the personal information regarding the identities of sexual partners and their contact information is used only for reaching partners to warn them of their disease risk and to connect partners with testing and other resources. Unless contacted by a partner for follow-up conversations or additional questions, no other contact is initiated by the disease investigator. Third, in the case of anonymous notification, disease investigators are prohibited from sharing any information that could lead to the identification of the index patient. When notifications are confidential, disease investigators are still strictly prohibited from divulging any personal information that has not been approved by the index patient. Finally, notification must be undertaken in a manner that does not expose partners to undue harm. Only reasonable attempts can be

made to reach a partner (e.g., three phone call attempts instead of ten attempts), detailed messages revealing sensitive information cannot be left on voicemails or communicated to family, friends, or other parties, and messages are carefully tailored to sufficiently inform partners that they can seek testing in their local community, as well as the availability of other health and social services should they be needed.

Online partner notification has been developed in a way that also attempts to lessen the burdens to index patient and partner privacy and confidentiality. In the notification systems developed by Manhunt and inSPOT, messages can either be anonymous or confidential, but regardless of which format is chosen, are sent from messaging systems that do not identify the index patient in the account name or in the message title. The identity of sexual partners need not be disclosed at all in online partner notification because messages are either sent to the partner's hookup site account or an email address, and those messages cannot be forwarded or intercepted by unintended third parties during the transmission. The privacy and confidentiality of online partner notification users are further protected by the safety measures put into place by both companies. Messages are sent from servers designated only for the use of partner notification, and the data that are collected on partner notification are stored for limited time periods (thirty days), after which they are destroyed. There are no backend servers used to collect additional information about these notifications, and no information is ever sold or made available to outside parties.

Online partner notification systems have been configured to adapt to or handle the privacy and confidentiality pitfalls that so many services and industries have encountered

in the digital age, and have done so in a way that also takes into consideration the potential for ethical and legal breaches that offline partner notification has worked to lessen over the last several decades. Risks to the privacy and confidentiality of patients and their partners still remain to some degree, however, no matter what form the notification may take. Index patients who volunteer to notify partners must share some private information about their personal health and their sexual activity, and partners must accept that some pieces of their own sexual lives and contact information will be used to warn them about a possible health risk. In order to achieve the benefits of partner notification, which will be discussed later on, and to attempt to reduce disease transmission, some privacy infringements are necessary, and the belief that all of this communication will be locked away under the strictest confidences is idealistic. But both online and offline partner notification programs continue to guard against unnecessary and unethical intrusions into these areas of ethical concerns to prevent additional burdens from being thrust upon those who need the assistance that partner notification can provide.

2. Liberty and Self-Determination

The burdens to liberty and self-determination only require a brief review because in either offline or online partner notification, the risks for index patients are low and the harms that may be experienced by sexual partners are inevitable. Index patients are given the important choice as to whether they want to initiate HIV/STD partner notification for their sexual partners. This is a choice that is left entirely to the patient's discretion, but it is the duty of public health departments to ensure that the decision is informed by a

discussion of the benefits and drawbacks that can come from participating in partner notification. How the notification process is carried out is left largely to the wishes of the patient. Disease investigators can assist patients using both Manhunt and inSPOT, guiding the patient's through each step of the process to ensure their choices are informed. Additionally, inSPOT affords the patient the opportunity to control every aspect of how his partners will be notified should the patient choose to use this system on his own.

Sexual partners have less autonomy in that they cannot control if and how they are contacted. Like the relinquishing of some privacy interests, this liberty burden is an unavoidable feature of partner notification that can only be diminished by so much. One way to balance against the burden of an unexpected partner notification message is by connecting them almost instantaneously to health resources so that they can take advantage of the information that is presented to them. Given that so much of our daily lives and our communications are now mediated by the online world, the ability to receive partner notification messages through an online forum may be more appealing (and less threatening) to at-risk partners who can then immediately connect to online health resources. This level of interconnectedness between notification message and health resources can prove useful for displacing some of the burdens to autonomy partners can experience during the notification process, providing a partner that is startled by a notification message some sense of control over the next steps that need to be taken to proactively seek HIV/STD testing.

v. *Question Five: Is the Program Implemented Fairly?*

Question five of this ethical framework overlaps with the discussion of the burdens to justice that can arise in public health programs, with this specific question looking to issues of distributive justice and the requirement that the benefits and burdens of an intervention be fairly apportioned across the population.¹⁷³ The benefits of a public health program cannot be directed to only one community, nor can another community bear the brunt of the burdens a program can create.¹⁷⁴ Discrimination in any form, and towards any particular group or groups of people, is intolerable in public health just as it is in law, and it is critical that an intervention not create or perpetuate social harms or deleterious health effects in the name of helping some at the expense of others.

Offline and online partner notification meet this ethical requirement. Since its inception, partner notification has been used as a method of disease surveillance and prevention applicable to all segments of society. In fact, Thomas Parran's conception of partner notification was not because of the health effects syphilis was having on specific segments of American society, but it was because of the existence of this disease across every nook and cranny of the U.S. population.¹⁷⁵ Within the offline context, partner notification services are situated in public health clinics where any member of the general public can seek out testing, counseling, and other services related to HIV and STDs. These services include partner notification programs, where disease investigators will work with anyone who has been diagnosed with HIV or an STD to notify their sexual

¹⁷³ Kass, *supra* note 118, at 1780.

¹⁷⁴ *Id.*

¹⁷⁵ See BRANDT, *supra* note 37, at 122–60 (describing Thomas Parran's public, and often contentious, campaign to change the way syphilis prevention, testing, and treatment was conducted in the United States).

partners. No one is turned away because of who they are or who their partners are in terms of race, gender, sexual orientation, or any other mutable or immutable characteristic. But just because partner notification is available to everyone does not mean it is necessarily targeted at all demographics equally. As its history demonstrates, partner notification has regularly been directed at those communities where the burden of HIV and other STDs is greatest. Throughout the 1980s and 1990s, partner notification for HIV was focused on gay and bisexual men.¹⁷⁶ As the presence of that disease has shifted across the general public into other populations, such as the African-American and Latino communities, so have the efforts of partner notification.¹⁷⁷

Justice can be obtained within this type of public health framework. This need not require that partner notification be held up to a utilitarian aim of maximizing the collective health of the entire population, where the focus is on increasing the overall health of the population regardless of how those goods are distributed. Instead, as Faden and Powers argue, justice within public health is not “indifferent to the poor health outcomes of some so long as overall health is increased.”¹⁷⁸ Distribution does matter, and

¹⁷⁶ See Bayer & Toomey, *supra* note 50, at 1159.

¹⁷⁷ See, e.g., Patrica Kissinger & David Malebranche, *Partner Notification: A Promising Approach to Addressing the HIV/AIDS Racial Disparity in the United States*, 33 AM. J. PREVENTATIVE MED. S86, S87 (2007) (“The keys to success with [partner counseling and referral services] among diverse racial/ethnic populations may ultimately lie in the attention paid to unique cultural approaches that ensure confidentiality, lack of coercion, and respect for the unique concerns, beliefs, and sensibilities of individuals who make up these communities. In so doing, health professionals can gain the trust of the individuals they are trying to reach, and complete the process of partner notification in a manner that achieves the goals of [partner counseling and referral services] with minimal harm to the populations served.”).

¹⁷⁸ R.R. Faden & M. Powers, *Health inequities and social justice: the moral foundations of public health*, 51 BUNDESGESUNDHEITSBL GESUNDHEITSFORSCH 151, 152 (2008).

therefore, an unequal distribution of benefits can be just.¹⁷⁹ Too often public health can be caught up in measuring the quantifiable, epidemiological attributes of health: whether or not morbidity and mortality has increased or decreased, or whether the incidence, prevalence, or both, of a disease has been affected by an intervention. These data, of course, are certainly important. However, who has an opportunity to experience improved health and how those opportunities materialize can be equally just and legitimate ends for public health endeavors. When disparities in health exist, justice requires that those obstacles be better understood and lessened in order for groups who shoulder the burden of poor health outcomes to have the promise of a more healthful future. As Faden and Powers state, “Inequalities in health that are a part of such systematic patterns of disadvantage are the inequalities that are most morally urgent to address. Justice here demands aggressive public health intervention to document and help remedy existing patterns of systematic disadvantage and their detrimental consequences.”¹⁸⁰

In many ways, online partner notification exhibits this redistribution of goods in order to better serve those groups who may need this intervention most. The online partner notification systems developed by inSPOT have been created to be open to anyone who would like to use these sites to reach sexual partners. The sites are not maintained or affiliated with a specific hookup site, and they partner with state and regional public health departments to promote their availability to their respective surrounding communities. Manhunt’s partner notification is different. It is designed and maintained by Online Buddies whose users are statistically at a greater risk for becoming

¹⁷⁹ Kass, *supra* note 118, at 1781 (“Several notions of justice allow and even require unequal allocations of benefits to right existing inequities.”).

¹⁸⁰ Faden & Powers, *supra* note 178, at 153.

infected with HIV or an STD, and where a proportion of its users are already HIV-positive. Manhunt's notification site is intended to provide services to gay men who are disproportionately affected by STDs, and this closed system offers a unique opportunity to bestow public health avenues in a setting that is not available to the rest of the population. And this is justified. Manhunt's online partner notification is concentrated on a population where the disease burden has been and continues to be considerable, and allocates the benefits of partner notification services accordingly to a community that needs those resources more than others. Given the availability of Manhunt's notification system to its hookup site members, this could very well translate into greater awareness of issues around HIV and other STDs for the site's online community as well. Those segments of the U.S. population that are shut out of this notification system are not without options for partner notification services, such as inSPOT, or other growing notification tools that exist both online and offline.

vi. Question Six: How Can the Benefits and Burdens of a Program be Fairly Balanced?

The final step of the public health ethics framework is a determination as to whether the expected benefits of the program can justify the identified burdens. Kass acknowledges that this can be a complicated, if not contentious, decision in the policy arena because of how different constituencies are bound to disagree over just how burdensome a policy or program should be, and whether those anticipated burdens are justified in light of the good that can be achieved for the public's health.¹⁸¹ Nonetheless, Kass stresses that it is key for policy makers to prevent the implementation of programs

¹⁸¹ Kass, *supra* note 118, at 1781.

that are unethical “whether because of insufficient data, clearly discriminatory procedures, or unjustified limitations on personal liberties.”¹⁸²

1. Benefits to the Public

Partner notification, be it online or offline, is beneficial to the public in that it provides a mechanism that can be utilized for tracing the transmission of an STD and for the identification of potentially exposed sexual partners, all of which can be used to stop the further spread of disease throughout the general population. Partner notification has the ability to identify who may need the assistance of public health for testing, treatment, or other social services, while also determining who is not at risk—an equally beneficial determination in terms of resources used and lives potentially disrupted. Whether the disease in question is the transmission of antibiotic-resistant gonorrhea in a small group of individuals, or a larger outbreak of syphilis that cuts across numerous demographics and locations in a community, partner notification has the potential to be a valuable instrument to guard the public’s health.

Online partner notification adds to this public benefit by taking advantage of digital technologies to inhibit disease transmission that may come from online or offline interactions. This form of notification has grown out of the online analyses of disease transmission in online chat rooms, and is envisioned as a prevention tool that could be implemented in online environments where more and more men look to find sexual partners. Not only do those who look for sex online benefit from having disease prevention tools that are merely a click or a swipe away, but the larger public can also choose to use these systems to communicate with sexual partners via online gadgets that

¹⁸² *Id.*

are not that distinct from the other technologies that facilitate communication throughout so many other facets of their lives. Furthermore, while offline partner notification has been criticized for the amount of resources needed to carry out notification activities (e.g., time, personnel), its online brethren offers a more efficient and user-friendly setting that can quickly and easily reach a patient's sexual partners, and may serve as a reminder to online hookup users that these services are readily available and that partner notification is an important endeavor.

2. Benefits to Individuals

The benefits of partner notification for individuals involved in the process are considerable given the health outcomes that can be achieved. For index patients, having to notify partners fulfills their ethical obligation to warn their sex partners of their possible exposure. This is not a task one wants to undertake, however. Telling others that you have an STD and that they might have been exposed at some point can be a terribly difficult, uncomfortable, and even dangerous position. Yet while it may not be a pleasant activity to initiate, partner notification allows index patients to help others and to hopefully steer sexual partners towards the resources they may need to best protect their personal health. Online partner notification is no different in this regard, except that it allows index patients to select what may be a more efficient, or possibly a more comfortable, means to reach out to their sexual partners. As discussed above, the notification site offered by inSPOT allows index patients to entirely control the notification process given the capability to send out messages on their own, and Manhunt's notification program only requires that the patient know the user handle of his

sexual partners to establish communication—nothing more is needed given the assistance of disease investigators.

Partners are benefited by being informed of their potential exposure to HIV or an STD, and then having the opportunity to use this information to seek out testing and medical care, should they so choose. Like the circumstance of index patients, this benefit is paired with the burden of having to confront what may be an unexpected health problem that's gravity is unknown. Nonetheless, the notification message partners receive allows them to make the autonomous decision as how to best proceed. Online partner notification, once again, provides a swift medium to receive this notification as well as to instantaneously connect to other online resources that can help them parse through the decision-making process. InSPOT allows partners to be reached by those they have either met online or offline. Manhunt's site has the advantage of being based on a confirmatory clinical test where the message is sent from an individual they have met on Manhunt's hookup site and with whom they later had sex.

vii. Balancing the Benefits and Burdens of the Kass Framework

Having addressed all of the questions posited by the Kass framework for public health ethics, the various benefits and burdens presented by offline and online partner notification must be compared in order to ascertain whether these HIV/STD prevention tools fairly balance the positive and negative implications of their use. Because the macro-level issue of effectiveness is distinct from the ethical discussion of benefits and burdens in that the effectiveness of partner notification operates at two levels (individual and the public) and because so much uncertainty around the effectiveness of partner

notification exists, the effectiveness and cost-effectiveness of partner notification will be discussed first. Then, the balancing of benefits and burdens for index patients will be addressed, followed by the balancing for sexual partners.

1. Effectiveness

There is no doubt that these systems are used by index patients and disease investigators to reach out to sexual partners. But just how frequently these programs are used, whether the notification messages are received by partners, and whether or not those messages are translated into partners seeking out testing for a potential HIV/STD infection, has received little attention by the public health literature. As has been discussed above, the current data surrounding these questions make it difficult at best to arrive at a definitive answer. In order to begin ascertaining how regularly these notification systems are used and whether they get partners into a clinic for testing, more research and better data are needed.

Tied to the ambiguity around effectiveness is the question of cost-effectiveness. Because no one can matter-of-factly pronounce whether partner notification works, it is equally as challenging to arrive at a hard dollar amount about whether the investment into partner notification is worth the public funding it receives. One study of partner notification conducted in 1997 estimated that the cost of identifying sexual partners who tested positive for syphilis equated to roughly \$1,470 per partner in today's value,¹⁸³ but given the enhanced ability to reach partners via email, text, and cellphone, that number may no longer accurately represent the true costs involved. The only monetary valuation

¹⁸³ Fan, *supra* note 172, at 565–66 (citing Thomas A. Peterman et al., *Partner Notification for Syphilis: A Randomized, Controlled Study of Three Approaches*, 24 SEXUALLY TRANSMITTED DISEASES 511, 514 & tbl.2 (1997)).

of online partner notification is even foggier, with an estimate offered by Toronto Public Health to be around ten dollars per notification message sent via inSPOT if six messages are sent per week.¹⁸⁴

The value of partner notification must be cast in terms of how effective this public health tool is vis-à-vis other alternatives. Remember: partner notification exists not only to reduce disease transmission throughout a community, it also serves as a method of communicating sexual risk and disease exposure information between individuals. Neither of its intended goals can be considered in isolation, and as Kass recognizes, the effectiveness of partner notification need only be reasonable. While it may seem expensive (or inexpensive) in terms of time, money, and resources to notify a sexual partner and get him tested for HIV and other STDs, the consequences of not having partner notification available to alert him of his risk and then guide him to testing and treatment could be dire. Many STDs can be transmitted through skin-to-skin contact or through the exchange of bodily fluids, and the possibility that an individual can be asymptomatic is real, meaning that the transmission of an STD can happen without the patient or the partner's knowledge. And if an individual is asymptomatic, he can carry the bacteria or virus for months and years if he is not tested, transmitting the infection to others. Partner notification exists to stop this pattern of transmission, and provides a communication strategy and assistance from disease investigators dedicated solely to curtailing new infections and preventing reinfections from taking place. Without these

¹⁸⁴ COLIN LEE & MAYANK SINGAL, EVIDENCE REVIEW: NEW TECHNOLOGIES FOR PARTNER NOTIFICATIONS FOR SEXUALLY TRANSMITTED INFECTIONS 6–7 (2013), *available at* https://cdn.metricmarketing.ca/www.nccid.ca/files/Evidence_Reviews/Partner_Notification/New_Technologies_STI_EN.pdf.

systems, index patients and partners could face even greater obstacles in communicating this important health information to those who are possibly exposed, or leave many in the dark without guidance on how to seek out testing and treatment when they are needed. Even if a large number of index patients choose not to use partner notification, it still can hold tremendous potential and actualized value for those who need it most when they are confronted with the realization that they might have an STD.

2. Benefits and Burdens for Index Patients

When an index patient must come to terms with his positive diagnosis for HIV or another STD, he must also acknowledge that he contracted the illness from someone who may or may not be aware of his respective health status, and that the index patient may have potentially exposed others through sexual contact. Partner notification, either offline, online, or both, can benefit the index patient by allowing him to fulfill his ethical duty to warn his sexual partners of a possible threat to their own personal health. By reconnecting with past or current sexual partners to communicate that he has an STD, an index patient is providing potentially valuable health information that can be used to facilitate the improved health of not only his sexual partners, but also the wider community. But with this good comes difficulties. Index patients must overcome the discomfort and concerns with revealing this information to his partners and disease investigators, while also having to grapple with the fear that the partner may guess the source of the infection (where he has chosen to be anonymous) and the possibility that others outside of the direct communication may learn about his infection. Just how challenging these burdens to privacy and confidentiality are depends on numerous

factors, including the method of notification, the number of partners, the seriousness of the condition, concerns surrounding the shame and stigma that go hand-in-hand with HIV and other STDs, and the impact this unfortunate news will have on any number of relationships.

Burdens to the index patient's privacy and confidentiality may be onerous. However, it is critical to remember that partner notification is an entirely voluntary choice for index patients. While public health officials have the duty to ensure a patient's choice is informed, for almost all cases, there are few constraints on the patient's liberty because the choice to utilize partner notification is entirely his.

In the purely online avenue of partner notification, the burdens that an index patient can experience may be lessened when compared to those experienced offline. The two systems discussed here can balance the benefits and burdens of online partner notification in different ways. Manhunt's online partner notification system requires very little personal information to be disclosed by the index patient except for his confirmatory HIV/STD test result and the usernames of his sexual partners, unlike offline partner notification where the index patient must share his sexual history, as well as the names and contact information of his sexual partners. With nothing more than these two pieces of information in the Manhunt partner notification system, a disease investigator can send a notification message to sexual partners the index patient has met within Manhunt's hookup site. The setup of inSPOT's site has the potential to decrease privacy and confidentiality burdens by removing the assistance of public health workers altogether. The index patient does not have to divulge the details of his sexual history or the

identities and contact information of his sexual partners with a disease investigator. Because inSPOT's system is entirely user-driven, the index patient controls what information he provides to his partners and when the process takes place. What might give index patients pause, however, is how they perceive either of these online systems. Whether or not an index patient chooses to use inSPOT or Manhunt's notification system (assuming he's a member of the Manhunt hookup site), may hinge on whether he feels that he can trust one system over another. Should he worry that his privacy and confidentiality are at great risk with a for-profit company's notification system given that it is housed within a gay hookup site and largely staffed by members of the gay community, he may prefer other means for notification or bypass notification entirely for fear that his information could be leaked in the online and offline gay communities.

3. Benefits and Burdens for Partners

The benefits of partner notification, both offline and online, are considerable when it comes to the health and well-being of sexual partners. The two main goals of partner notification hinge on whether an index patient's sexual partners are effectively reached by the notification message, and whether those messages are then translated into sexual partners seeking out testing for HIV and other STDs and then receiving medical care for a confirmed infection. Partner notification warns partners of their risk of possible exposure to an infectious disease because of their previous sexual contact, and provides them with the opportunity to determine what the next best step is for guarding their personal health. For illnesses such as gonorrhea or syphilis, partner notification can alert partners about a curable bacterial infection that can easily be treated before it is

transmitted to others or before the infection advances to more serious stage. The early detection of HIV, by comparison, allows the partner to seek out antiretroviral treatment in order to manage the virus and bring his viral load down, thereby decreasing the likelihood of exposing others to the illness, and in the long run, protecting his own health. And should the partner be reached early enough after he has been potentially exposed to HIV, the availability of post-exposure prophylaxis may provide a partner with a chance to take antiretrovirals to possibly prevent acquisition of HIV.¹⁸⁵ A notification message can bolster the autonomous decision-making of a sexual partner by giving him the information he may need and want to avoid further harm to himself and to others.

The burdens that these benefits must be balanced with are also very real. Partners have no say in whether or not they want to be contacted about an STD, and whether they want their identities and snippets of their sexual histories revealed to third parties, regardless if that party is a disease investigator. Depending on what information is shared in the message, a notification can place a varying burden on a partner's liberty and self-determination. A partner notification message can abruptly disrupt a partner's life and force him to grapple with uncertain health issues that he may not want to address. Furthermore, he may now have to reconnect with his own past sexual partners, which may place him in uncomfortable or even dangerous situations that he cannot foresee.

As with index patients, online partner notification could potentially alleviate some of these burdens, or at least reduce their severity. A notification email or e-card may be

¹⁸⁵ *Post-Exposure Prophylaxis*, AIDS.gov, <http://aids.gov/hiv-aids-basics/prevention/reduce-your-risk/post-exposure-prophylaxis/> (last visited July 13, 2014) (“Post-Exposure Prophylaxis (PEP) involves taking anti-HIV medications as soon as possible after you may have been exposed to HIV to try to reduce the chance of becoming HIV positive. These medications keep HIV from making copies of itself and spreading through your body.”).

perceived as less jarring than a confidential phone call from a health department given the growing use of email and text messaging over phone calls in the present day,¹⁸⁶ and the digital medium may be more conducive to identifying next steps for HIV/STD testing and clinical care via online resources assuming that these resources are immediately available. A partner may feel less publicly exposed by receiving a private message to an email inbox or personal account, allowing him to review the message at a time and place most amenable to him depending on the seriousness of the message's content.

There exists uncertainty around these programs, not only in terms of the macro issues of cost and effectiveness, but also on the individual level. Each notification message that is conveyed either through an email message or a face-to-face conversation is unpredictable in the benefits and burdens it will bestow on index patients and their partners. For an index patient who is unscathed by news of an STD and agrees to engage in notification, and who then messages a past sexual partner who is already aware that he's been exposed, the benefits and burdens of partner notification are not entirely clear. Yet variations on this situation are routinely played out across the country, eliciting entirely different experiences and outcomes for the individuals involved and for the public as a whole.

Even in the face of such uncertainty, online partner notification and offline partner notification possess tremendous promise for guiding individuals through the taxing health dilemmas that HIV and other STDs present. When a person is diagnosed

¹⁸⁶ See, e.g., AARON SMITH, AMERICANS AND TEXT MESSAGING, PEW RES. CTR. 1–14 (2011), available at <http://www.pewinternet.org/files/old-media/Files/Reports/2011/Americans%20and%20Text%20Messaging.pdf> (finding that thirty-one percent of Americans prefer receiving text messages over voice calls, and how texting is much more utilized by younger generations than older).

with a potentially life-altering infection, it becomes quickly apparent that the acquisition of this infection did not take place within a vacuum. This index patient was infected with this disease because of his contact with another infected individual, and equally, the index patient may have unknowingly exposed others to that disease prior to his diagnosis. An inextricable bond has been formed from sexual encounters, a bond that some participants may not wish to sustain in any form. But with this bond comes ethical and moral duties to warn partners about a communicable disease that can have very serious health ramifications down the line. With these individual duties also come the overarching efforts of public health departments to contain and alleviate disease burdens across communities and the public-at-large. Online and offline partner notification provide index patients, sexual partners, and public health a medium with which to communicate information that can quite literally save lives in the event the illness is HIV or a drug-resistant bacterium or viral infection, or in less severe circumstances, stop the spread of infections that are easily curable.

It is argued here that both online and offline partner notification do fulfill the ethical requirements set forth by the Kass framework. What is key is that these systems exist and continue to be operated in a manner that protect against intrusions into the liberties of patients and partners who engage in partner notification activities. Offline partner notification has been implemented for several decades in a manner that sets out to guard the identities of the participants as well as the content of the health warnings being exchanged. Online partner notification has followed these safeguards and adapted them to

the online world given the newfound ways in which people interact and look for sex in an increasingly digitized society.

These systems are by no means perfect, however. They have been conceived of and operationalized in a way that meets the public health goals of having a system where patients can anonymously or confidentially reach out to their partners, and where partners can then take this information and use it to better understand and protect their health. Prank emails, incorrect telephone numbers, or simply word-of-mouth gossip can exacerbate the potential for harms to partner notification participants and public health outreach, yet steps have been taken by the systems discussed herein to reduce the likelihood of such fallout. Moreover, these current notification programs continue to fill a need in HIV and STD prevention. Partner notification offers an opportunity to communicate serious health issues where once no such opportunity existed. Were these systems to be eliminated entirely, a great need to communicate sexual health information would continue to exist and disease prevention efforts in those communities that need it most would be undermined.

V. CONCLUSION

a. **The Future of Partner Notification: An Increasingly Tech-Driven Approach**

Offline and online partner notification are tools in the public health arsenal that provide people with opportunities to help better protect their own health and the health of others in a manner that is ethical. And when taken together, these voluntary acts help to

chisel away at the stubborn rates of HIV and other STDS that have remained too high for too long. While the effectiveness of these interventions remain questionable and open to debate, their elimination from the cadre of intervention options would almost certainly exacerbate potential harms to the health of patients, partners, and the broader population. But in order to stay relevant as a viable path for disease prevention, partner notification has had to adapt to the changing circumstances in which people meet and communicate with one another. It has moved out of the purely clinical setting of the doctor's office and the public health clinic and into the communities and environments where people live, as well as the sexual spaces from which risk behavior and disease can also emanate. This is why partner notification has moved online, and this is why it may have to tweak its identity even more so with the ever-changing natures of technology and disease transmission patterns.

When the idea for this project was launched in 2009, hookup sites such as Manhunt, Adam4Adam, and Craigslist (specifically, its M4M singles section) were popular venues for men to find sexual gratification, and the online partner notification websites produced by YTH and Online Buddies were the models noted in the press and the public health literature as disease notification instruments setting the standard for reaching sexual partners meet online and off.¹⁸⁷ And then came the smartphone. Not to mention over one million apps that have been developed to play games, procure Starbucks Rewards points, and of course, find sex. Just as the laptop and hookup websites were to the late 1990s and 2000s, the smartphone and hookup apps have been for the late

¹⁸⁷ See e.g., David Tuller, *After Hookups, E-Cards That Warn, 'Get Checked'*, N.Y. TIMES, Jan. 9, 2009, http://www.nytimes.com/2009/01/20/health/20partners.html?_r=0 (discussing the two systems offered by YTH and Online Buddies).

2000s into the present. What was once a marketplace for sites such as Manhunt and Gay.com, has now been overtaken by apps such as Grindr, Scruff, BoyAhoy, and so many others. In fact, the field of hookup apps is so expansive that a simple search for “gay chat” in Apple’s App Store returns 166 unique results, catering to all demographics and sexual proclivities within the gay community. Even older hookup mainstays have thrown their hats into the app ring, with several hookup websites developing app-versions of their websites,¹⁸⁸ or, like Online Buddies has done, purchasing app companies and incorporating them into their brand.¹⁸⁹ The ways in which HIV/STD partner notification is adapting to this shift are just now beginning to be explored.

Given that the most popular device for communicating quickly and easily has become the smartphone,¹⁹⁰ a variety of start-up companies have jumped at the chance to develop app and text-based communication systems that will allow index patients to share with sexual partners their HIV/STD test results or anonymously notify partners via partner notification-specific text messages. The system that has perhaps gained the most notoriety in the last year has been Healthvana (formerly called Hula),¹⁹¹ a smartphone app that lets a patient upload his latest HIV/STD test results in an decipherable format, and then allows the patient to share these results with his past, present, and future sex

¹⁸⁸ For example, companies/brands such as Adam4Adam, Manhunt, and Gaydar have created app versions of their popular hookup websites.

¹⁸⁹ In 2013, Online Buddies, Inc. acquired the gay hookup app Jack’d, which reportedly has five million users around the world and ten thousand installs each day. Press Release, Online Buddies, Online buddies acquires gay dating app Jack’d (Nov. 13, 2013), *available at* <http://online-buddies.com/2013/11/online-buddies-acquires-gay-dating-app-jackd/>.

¹⁹⁰ See AARON SMITH, SMARTPHONE OWNERSHIP – 2013 UPDATE, PEW RES. CTR. 1–12 (2013), *available at* http://www.pewinternet.org/files/old-media/Files/Reports/2013/PIP_Smartphone_adoption_2013_PDF.pdf (finding that fifty-six percent of Americans now own smartphones).

¹⁹¹ HEALTHVANA, <https://www.healthvana.com/> (last visited Dec. 11, 2014).

partners.¹⁹² The Healthvana system operates in the following manner: a patient downloads the app to his phone, and then after setting up a unique, password-protected profile that includes a username and even offers the user personal touches such uploading profile pictures (much like Facebook), the patient then enters the name and contact information of his clinic and sends a request to that clinic via Healthvana asking the clinic to upload his latest test results once they are ready. On the other end of the transaction, personnel at Healthvana work with the clinic by filling out a HIPAA information release form that gives the designated clinic permission to share the requested test results.¹⁹³ Once the test results are available at the clinic, the results are then sent to Healthvana where they are then entered into the app system in an easy-to-understand format (e.g., “nonreactive for HIV” becomes “HIV: negative”) and made available to the patient.¹⁹⁴ When the patient wishes to share his test results, he can either

¹⁹² See Dina Fine Maron, *You've Got Mail . . . About STDs*, SCI. AM., Nov. 21, 2013, <http://www.scientificamerican.com/article/youve-got-mail-about-stds/> (“To access your results or show them to others in a fairly light-hearted way, you go to a screen covered by the image of a closed zipper and unzip the image with your finger, gradually revealing the information underneath. Or, you can “friend” others to allow them to securely see the results via their digital devices. The app also lets users review STD testing centers with Yelp-like reviews about their experiences.”).

¹⁹³ *Frequently Asked Questions: How do I get my results?*, HULAHQ.COM, <https://www.hulahq.com/faq/#how-it-works> (last visited July, 13, 2014) (“Typically, the process is as follows[:] You register for a [Healthvana] account and fill out information about yourself and where you were tested. After you sign your name with your mouse or finger, we use the personal information you entered to automatically generate a medical records request form that complies with HIPAA. We then attach your signature and send this form to your provider. Your provider receives the request and sends your results back into your secure [Healthvana] Account. Your results are encrypted within the Hula system and no one can see your results except for you and the [Healthvana] employee processing your results. Once your results are in your account, you can store and share them however you choose!”).

¹⁹⁴ Maron, *supra* note 192 (“Then a trained [Healthvana] employee taps the results into a set template so that it will be understandable. Instead of a syphilis test finding saying you are ‘nonreactive,’ for instance, the app will say that the person is ‘negative’ for syphilis.”).

text, email, or copy an invitation link that grants the specified partner access to his profile.

Another system that has garnered a modicum of attention is Don't Spread It.¹⁹⁵ Don't Spread It is simpler in its design than Healthvana in that it is a text-messaging system where index patients can easily notify partners about a potential exposure. All a patient has to do is visit dontspreadit.com, select one or more applicable STDs for which the patient has tested positive, and then enter an email address or phone number for his partners and then click "send." A partner will receive a text message that directs him to dontspreadit.com where he is then informed of the infections to which he may have been exposed, along with information about those various diseases, immediate precautions to take, and links to clinical services and support programs. What is unique about this particular system is that the patient can create a secure account where he can see if and when a notification message has been opened, as well as receive alerts to his phone when a message has been viewed.

Systems such as Healthvana and Don't Spread It are start-up ventures that help to demonstrate the continuous evolution taking place in an increasingly sophisticated field of disease prevention. Rather than the organic processes with which inSPOT and Manhunt's partner notification sites have developed and continue to function—in concert with state and city public health departments, and regularly assisted by public health disease investigators—this latest batch of products has been the creation of ingenious engineers and charismatic CEOs who have identified potential gaps in how people send

¹⁹⁵ DON'T SPREAD IT, <https://dontspreadit.com/> (last visited July 13, 2014).

and receive disease notification information.¹⁹⁶ But like the online partner notification systems of Manhunt and inSPOT, these new systems are also raising concerns about data privacy, security, and just how successful these newfangled instruments will be in empowering individuals with knowledge about their HIV/STD status, and whether they can be utilized to stem the transmission of HIV and other STDs around the country.¹⁹⁷

b. Final Thoughts

Partner notification has been a cornerstone of STD prevention in the United States that has survived dramatic changes in ways in which people meet and interact, the novel diseases that have been exchanged through those interactions, and the continued attempts to remove the burden of disease and injury from the American population. Public health departments have been charged with the immense task of carrying out partner notification duties in their respective communities, and along the way, for-profit and nonprofit entities have joined the crusade to provide novel avenues for taking an entirely offline means of HIV/STD prevention and adapting it to the communication modes that now dominate so much of our daily lives. As more products come to the market with the intent of assisting efforts in the ongoing battle against HIV and other STDs, partner notification will likely be altered in slightly different ways in order to maneuver a social and

¹⁹⁶ See, e.g., Edward C. Baig, *Hooking up at SXSW? Hula app can help you test for STDs*, U.S.A. TODAY, Mar. 7, 2014, <http://www.usatoday.com/story/tech/columnist/baig/2014/03/07/hula-app-can-help-you-test-for-stds/6126453/> (interviewing Hula's CEO, Ramin Bastani).

¹⁹⁷ See Maron, *supra* note 192 (“Still, legal concerns about turning over STD results to someone other than the patient prompted [San Francisco’s] STD testing services to turn away patients’ requests to send test information to them via Hula—even though Hula facilitates filling out a Health Insurance Portability and Accountability Act form that gives clinics permission to share the data for each Hula user.”).

technological landscape that is dramatically changing in ways most cannot currently fathom.

What is important for partner notification systems such as inSPOT and Manhunt is that they protect the interests and liberties of the vulnerable patients and partners who rely on these programs to steer their immediate health concerns, and that they be available and accessible to all who find themselves dealing with an infection they most likely did not anticipate. As the Kass framework clearly demonstrates, such protections and availability bring with them benefits and burdens to the parties who are thrust into the partner notification equation. For every plus that comes with an enhancing an index patient's privacy or autonomy, there is subsequent minus for either the patient or his partner that must be carefully balanced so that the promise of partner notification is not overshadowed by concerns or fears that too much is being sacrificed to better protect an individual or the public from harm.

Online partner notification and offline partner notification are ethically appropriate models of health promotion and HIV/STD prevention that should continue to operate and be accessible to all who choose these services regardless of who they are and how they may have been exposed to any number of STDs. Efforts to increase their ethical appropriateness should continue, however. For example, public health clinics and health care personnel should engage in the greater promotion of partner notification services in order to make patients more aware that these resources exist, thereby lessening the stigma and shame index patients may encounter in implementing partner notification messages and that partners may feel when receiving messages. Furthermore, in an era where data

breaches continue to reveal highly personal information, concerted efforts are needed to enhance the security around these disease communication mechanisms. Researchers must also work to refine how the effectiveness of these programs are defined, perhaps looking at these instruments collectively rather than in isolation, in order to more appropriately measure their ability to be used by individual patients and partners, and overall, decrease rates of HIV and STDs. But as debates abound throughout the United States about the rights of individuals and their behaviors versus the protection of the public's welfare in terms of health and wellbeing, be it vaccination mandates or taxes on sugary sodas, partner notification will continue to remain a controversial means of intervention that delves deeply into the most intimate details of a person's life. And as the barriers that protect our inner most private lives are made even more porous by the technologies we use and the choices we make amidst redefined social norms, the ways in which we seek to prevent harms through disease and other maladies will need to be continuously scrutinized for the good they can bring and the harms they can accentuate.

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