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"Nuns Don't Get Cervical Cancer": A Reproductive-Justice
Approach to Understanding the Cervical-Cancer Prevention
Crisis in Ireland

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“Nuns Don’t Get Cervical Cancer”: A Reproductive-Justice Approach to Understanding the Cervical-Cancer Prevention Crisis in Ireland

FROM 2015 to 2018 scandals surrounding the human papillomavirus (HPV) and cervical-cancer screening in the Republic of Ireland revealed serious deficiencies in the nation’s health-care system. A misinformation campaign conducted in 2015 about the HPV vaccine resulted in a sharp decline in Irish vaccination levels, and in 2018 Ireland’s CervicalCheck screening program was revealed to be flawed. In the Scally Report (2018), a scoping inquiry into the problems at CervicalCheck, key informants pointed to the significant gendered failings of the Irish health-care system, noting that “there is a history of looking at women’s health services as being secondary,” “women and women’s rights are not taken seriously,” and “paternalism is alive and well.” The report identified the need for expert and committed attention to women’s issues within the health-care system.¹

Through an analysis of two scandals, the CervicalCheck screening program and the HPV-vaccination-misinformation campaign, this study investigates the cervical-cancer prevention crisis in Ireland through the lens of reproductive justice. HPV vaccination and cervical screening are health behaviors that illuminate the intersection of oppressions based on race, ethnicity, socioeconomic position, ability,

1. Gabriel Scally, *Scoping Inquiry into the CervicalCheck Screening Program* (Dublin: Department of Health, 11 Sept. 2018), <https://www.gov.ie/en/publication/aa6159-dr-gabriel-scallys-scoping-inquiry-into-cervicalcheck>.

age, gender, sexual orientation, and immigration status.² These categories are best analyzed through an approach that foregrounds concepts of reproductive justice, underscoring intersectional oppressions in women's health care and advocating for truth telling as resistance. Indeed, this article is among the first studies to apply a reproductive-justice approach to the issues surrounding cervical-cancer prevention and HPV vaccination.

Both the CervicalCheck screening program and the misinformation campaign about HPV vaccinations were rooted in unethical communication by the state and nongovernmental actors. Unethical communication is ingrained in hegemonic, paternalistic sociopolitical practices that mirror narratives of oppression based on gender, ethnicity, and nationality.³ By contrast, ethical communication is "socially oriented, empathically situated, and responsive to others."⁴ In the midst of Ireland's cervical-cancer prevention crisis, women and public-health advocates confronted unethical communication through digital intersectional communication by engaging in storytelling and truth telling about health, illness, and the body to confront, challenge, and change Ireland's health-care system. By privileging the voices of activists and experts in this article, I argue that the ways in which women and public-health advocates confronted the cervical-cancer prevention crisis in Ireland may be understood as a triumph of truth telling over the failure of unethical communication.

METHODS

This qualitative study was part of a larger research project investigating reproductive justice in Ireland. This project offers a novel multiple-methods approach incorporating a variety of sources. Through a Fulbright U.S. Scholars Grant, I completed document analysis, interviews with activists, and participant observation in Ireland from

2. Beth Sundstrom et al., "A Reproductive-Justice Approach to Understanding Women's Experiences with HPV and Cervical-Cancer Prevention," *Social Science & Medicine* 232 (2019): 289–97.

3. Andrew Tinker, "Communication Ethics and the Rejection of Paternalism in John Stuart Mill's *On Liberty*," *Communication Quarterly* 67:3 (2019): 312–32.

4. Annette M. Holba, "Review of Dialogic Ethics," *Language and Dialogue* 8:3 (2018): 490.

September to December 2018. Developing convergence of multiple sources of evidence provided data triangulation. To strengthen the reliability of the study, I followed Yin's principles to maintain a chain of evidence and organize the data collected for the study into an evidentiary base that included documents, field notes, interview transcriptions, and narrative compilations.⁵ I received institutional review-board approval for this research.

The document-analysis portion of the study includes an investigation of published documentation on cervical-cancer prevention, including archival records and physical artifacts as well as traditional and social media. Archival research was conducted at the Boole Library, University College Cork, in its archival holdings of the records of the Attic Press, which included materials from the Irish women's movement covering the 1970s to the 1990s. I also conducted qualitative in-depth interviews with fifteen Irish activists working on reproductive justice; the quotations from activists in this article come from these interviews. In order to maintain the confidentiality of participants, all quotes from these interviews are included anonymously in this article. I also completed more than twenty hours of informal meetings and participant observation with experts and activists in Ireland. I collected publicly accessible documents (e.g., websites, press releases, reports, tweets, Facebook posts, YouTube videos, etc.) from twenty women's organizations. I also conducted searches of LexisNexis for relevant news articles (search terms: CervicalCheck, cervical cancer, screening, HPV vaccination, Gardasil). Finally, I searched for news and key figures on Twitter and Facebook to provide additional evidence.

Purposive sampling was used to recruit interview participants based on predetermined criteria that sought to include Irish women and men who were activists working on reproductive justice. First, key informants were identified as reproductive-justice activists in Ireland. I then contacted the leaders of Irish women's organizations. In addition, I asked participants to refer other activists, offering a "snowball" sampling approach to maximize requisite variety.⁶ Par-

5. Robert K. Yin, *Case Study Research: Design and Methods*, 5th ed. (Thousand Oaks, CA: Sage Publications, 2014).

6. Bruce L. Berg and Howard Lune, *Qualitative Research Methods for the Social Sciences* (Boston, MA: Pearson, 2012).

ticipants provided informed consent. A semistructured interview protocol allowed flexibility to facilitate a natural conversation-flow.

In-depth interviews were robust in length and scope, lasting over an hour at in-person locations convenient for participants or via Skype. To increase trust with participants and reliability of the results, I conducted all of the interviews. The existing literature and a reproductive-justice conceptual framework informed the development of the semistructured interview protocol.⁷ Participants were asked general questions about reproductive justice and women's health activism as well as specific inquiries about the CervicalCheck scandal and the HPV-vaccination-misinformation campaign. Data collection continued until theoretical saturation was reached, indicating that the themes emerging from these data were fully conceptualized.

Interviews were digitally recorded and transcribed verbatim. All data were combined into the evidentiary database.⁸ The reproductive-justice framework and a constant comparative method provided a rigorous, inductive approach to data analysis in order to identify patterns and themes across the data.⁹ HyperRESEARCH 4.5 qualitative-analysis software was used to facilitate open and axial coding to derive and develop concepts from the data.

CERVICALCHECK CANCER SCANDAL

Each year in Ireland more than 6,500 women receive surgical treatment for precancer of the cervix, 300 women are diagnosed with cervical cancer, and 90 women die from it.¹⁰ Among women 25 to 39 years of age cervical cancer is the second most common cause of

7. Herbert J. Rubin and Irene S. Rubin, *Qualitative Interviewing: The Art of Hearing Data* (Thousand Oaks, CA: Sage Publications, 2012).

8. Yin, *Case Study Research*.

9. Juliet Corbin and Anselm Strauss, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (Thousand Oaks, CA: Sage Publications, 2008).

10. Health Service Executive, "Human Papillomavirus (HPV) Vaccine: HPV (Human Papillomavirus)," *Health Service Executive*, 2021, <https://www.hse.ie/eng/health/immunisation/pubinfo/schoolprog/hpv/hpv-human-papillomavirus>, archived at <https://perma.cc/22A8-LTDM>.

death from cancer.¹¹ Almost all cases of cervical cancer are caused by HPV. Recent research suggests that widespread HPV vaccination and cervical screening could eliminate cervical cancer globally by the end of the twenty-first century.¹² In 2019 the World Health Organization (WHO) ramped up work to eliminate cervical cancer worldwide through a comprehensive approach to cervical-cancer control and prevention, including increasing HPV vaccination and appropriate screening and treatment.¹³

In Ireland CervicalCheck offers free cervical screening (formerly a smear test) to women in Ireland aged 25 to 60. The CervicalCheck cancer scandal first appeared in 2018 when it was revealed that over two hundred Irish women received false-negative screening-test results and were not informed of the error. Other failures included widespread nondisclosure of standard audits. Some of these women subsequently became ill from cervical cancer and sued Ireland's publicly funded health system, the Health Service Executive (HSE), among them Vicky Phelan, who refused to sign a confidentiality clause as part of her settlement and was thereby able to illuminate the failures of CervicalCheck. According to the Scally Report, over one million Irish women were screened between 2008 and 2015, with 1,067 cases of cervical cancer reported. Among those cases were 300 instances that required further review and 204 women who were found to have received incorrect results before they were diagnosed with cancer. Although letters were sent to their health-care providers, only 43 out of 204 women (or 1 in 5) were informed about the results of the audit. Ultimately, the CervicalCancer check scandal revealed that a significant number of women could have been diagnosed earlier and avoided terminal disease or death.

11. Health Service Executive, "Cervical Cancer: Overview," *Health Service Executive*, 2019, <https://www2.hse.ie/conditions/cervical-cancer/overview>, archived at <https://perma.cc/C7EG-AVWW>.

12. Kate T. Simms et al., "Impact of Scaled Up Human Papillomavirus Vaccination and Cervical Screening and the Potential for Global Elimination of Cervical Cancer in 181 Countries, 2020–99: A Modelling Study." *The Lancet Oncology* 20:3 (2019): 394–407.

13. World Health Organization, "Human Papillomavirus (HPV) and Cervical Cancer," *World Health Organization Newsroom*, 11 Nov. 2020, [https://www.who.int/en/news-room/fact-sheets/detail/human-papillomavirus-\(hpv\)-and-cervical-cancer](https://www.who.int/en/news-room/fact-sheets/detail/human-papillomavirus-(hpv)-and-cervical-cancer), archived at <https://perma.cc/9LCP-4XU5>.

HPV VACCINATION MISINFORMATION CAMPAIGN

HPV is a common sexually transmitted infection (STI), and most people will be infected with a form of HPV during their lifetime. The body typically clears HPV on its own; however, when the virus persists, it can cause changes to cells that lead to cancer over time. The HSE records that HPV causes 406 cancers in men and women every year in Ireland. A vaccine to prevent HPV infection has been licensed since 2006. Simms et al. report that 124 countries and territories include HPV vaccines in their national immunization programs.¹⁴ A school-based HPV-vaccination program for girls 12 to 13 years of age was introduced in Ireland in 2010. The vaccine currently used in Ireland is Gardasil 9, which prevents approximately ninety percent of HPV-related cancers.¹⁵ Over 270 million people have been vaccinated with Gardasil globally, including more than 260,000 people in Ireland. The Global Advisory Committee on Vaccine Safety considers HPV vaccines to be extremely safe.¹⁶

Despite the safety and effectiveness of the HPV vaccine, vaccine communication crises can result in low uptake. The WHO named vaccine hesitancy, which is the reluctance or refusal to vaccinate despite vaccine availability, one of the ten threats to global health in 2019.¹⁷ In 2015 a misinformation campaign targeting HPV vaccination appeared in Ireland. The antivaccination campaign targeted parents and gained widespread coverage on social media as well as in local and national media. Designed to undermine trust in vaccines, the campaign publicized unverified and false testimonials of side effects, health problems, and injuries allegedly caused by the HPV vaccine. National rates of vaccination plummeted in Ireland from approximately 87 percent to less than 40 percent of girls. However,

14. Kate T. Simms et al., "Impact of HPV Vaccine Hesitancy on Cervical Cancer in Japan: A Modelling Study," *The Lancet Public Health* 5:4 (2020): e223–e234.

15. Centers for Disease Control and Prevention, "Human Papillomavirus (HPV) Vaccination: What Everyone Should Know," *U.S. Department of Health and Human Services*, n.d., <https://www.cdc.gov/vaccines/vpd/hpv/public/index.html>.

16. Global Advisory Committee on Vaccine Safety, "Safety Update of HPV Vaccines," *World Health Organization Weekly Epidemiological Record* 92:2 (2017): 13–20.

17. World Health Organization, "Ten Threats to Global Health in 2019," *World Health Organization Newsroom*, 2019, <https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019>, archived at <https://perma.cc/S764-9KFB>.

a timely response brought the national average back up to approximately 75 percent in less than five years. According to the WHO, this vaccine-safety communication crisis was successfully addressed through coordination and engagement between key stakeholders, including health departments, immunization programs, influential public leaders, and the media.¹⁸ Activists in particular contributed to this successful coalition through truth telling.

REPRODUCTIVE JUSTICE: A CONCEPTUAL FRAMEWORK

In 1994 the International Conference on Population and Development (ICPD) declared that women's rights are human rights, and that these rights depend on each person's ability to determine if, when, and how to have children. Furthermore, the conference established that women's health relies on women's empowerment and gender equality. At a 1994 meeting advocating for health-care reform organized by the Illinois Pro-Choice Alliance and the Ms. Foundation for Women, a group of African American women met in Chicago to create the reproductive-justice movement, which centers the needs of women of color and other marginalized women who had been largely overlooked by traditional women's rights movements in the twentieth century.¹⁹ Although Black women, indigenous women, and women of color have often fought for reproductive rights and social justice, combining these efforts into a reproductive-justice movement purposefully uplifted the needs of the most marginalized women and communities. These efforts have since been popularized by initiatives such as SisterSong, whose former leaders include two of the women who met in Chicago, Toni Bond (Leon-

18. Global Advisory Committee on Vaccine Safety, "Communication about the Safety of Human Papillomavirus Vaccines," *World Health Organization*, 12 July 2019, <https://www.who.int/groups/global-advisory-committee-on-vaccine-safety/topics/human-papillomavirus-vaccines/communication-on-hpv>, archived at <https://perma.cc/2RBL-ZSKB>.

19. According to Ross and Solinger (2017, 277), "the twelve founding mothers of the concept of reproductive justice" included Toni M. Bond, Reverend Alma Crawford, Evelyn S. Field, Terri James, Bisola Maringay, Cassandra McConnell, Cynthia Newbille, Loretta J. Ross, Elizabeth Terry, "Able" Mabel Thomas, Winnette P. Willis, and Kim Youngblood. See Loretta J. Ross and Rickie Solinger, *Reproductive Justice: An Introduction* (Berkeley: University of California Press, 2017), 277.

ard) and Loretta Ross.²⁰ SisterSong, currently the largest national multiethnic reproductive-justice collective, defines reproductive justice as “the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities,” linking the movement explicitly to the demand for human rights and bodily autonomy for all people.²¹

Reproductive justice also offers a conceptual lens to understand women’s health in Ireland. Kimala Price observes that reproductive health and rights are connected to other social-justice issues such as education, poverty, housing, economic justice, environmental justice, immigration policy, prisoners’ rights, drug policies, and violence.²² This last category includes institutional and state-sponsored violence that impacts women’s reproductive health: colonialism, white supremacy, neoliberalism, criminalization, and capitalism. Contemplating the Irish context, Clara Fischer has highlighted “the stubborn persistence of the denial of reproductive rights to women in Ireland over the decades by arguing that deep-seated, affective attachments formed part of processes of postcolonial nation-building that relied on shame and the construction of the Irish nation as a particular, gendered place.”²³ The analysis here builds on research identifying the health-care system as a site of systematic oppression alongside state and church regulation of women’s reproductive lives and bodies in Ireland.²⁴ The cervical-cancer prevention crisis provides clear evidence for the relevance of reproductive justice in contemporary Ireland. As an Irish legal expert argued in an interview, these scandals reveal systemic issues: “There are questions there about consent, about women’s entitlement to knowledge about their own bodies, how women are spoken to when their reproductive function or sexual

20. Zakiya Luna, *Reproductive Rights as Human Rights: Women of Color and the Fight for Reproductive Justice* (New York: New York University Press, 2020).

21. SisterSong, “Reproductive Justice,” *SisterSong*, n.d., <https://www.sistersong.net/reproductive-justice>, archived at <https://perma.cc/XDF5-WUVN>.

22. Kimala Price, “What Is Reproductive Justice?: How Women of Color Activists Are Redefining the Pro-Choice Paradigm,” *Meridians* 10:2 (2010): 42–65.

23. Clara Fischer, “Abortion and Reproduction in Ireland: Shame, Nation-Building, and the Affective Politics of Place,” *Feminist Review* 122 (2019): 33.

24. Cara Delay and Beth Sundstrom, “The Legacy of Symphysiotomy in Ireland: A Reproductive-Justice Approach to Obstetric Violence,” *Advances in Medical Sociology: Reproduction, Health, and Medicine* 20 (2020): 197–218.

function is in question. There are questions about the gender dynamics that can take place between powerful and predominately male doctors and their female patients. There are questions about shame and stigma.” A reproductive-justice approach aims to understand and dismantle the systems of social inequality that shape, oppress, and restrict women’s health and reproductive rights.

The cervical-cancer prevention crisis in the 2010s was mitigated by health activists who applied reproductive justice to the Irish context. Leslie Sherlock has argued that this adoption of reproductive-justice approaches by Irish reproductive-rights activists in the twenty-first century has been essential, allowing them to become “more intersectional, more aware of and reflective upon our diversity, and especially more pensive about privilege.”²⁵ Scholars have likewise advocated for the use of a reproductive-justice lens—without appropriating it—to study contexts that have traditionally focused on white, educated, and able persons by considering biological, social, and economic inequities along with otherwise marginalized issues.²⁶ This call for a shift in paradigm has been extended to the study of health disparities in cervical-cancer prevention.²⁷ And yet to date a reproductive-justice approach has not become widespread in global research, undermining our ability to understand how to expand women’s agency and empowerment in preventing STIs and cervical cancer.²⁸

The adoption of this framework is especially important given the populations most at risk for illness. Marginalized populations, including uninsured and underinsured women, immigrants, and people of color, are at increased risk for HPV infection and HPV-

25. Leslie Sherlock, “Towards a Reproductive Justice Model in Ireland,” in *The Abortion Papers Ireland: Volume 2* (Cork: Attic Press, 2015), 81.

26. Catriona I. Macleod et al., “Articulating Reproductive Justice through Reparative Justice: Case Studies of Abortion in Great Britain and South Africa,” *Culture, Health, and Sexuality* 19:5 (2017): 601–15; Magaly Pirotte, “Using a Reproductive-Justice Framework: Organisational and Political Challenges” (conference paper, Abortion and Reproductive Justice Conference, the Unfinished Revolution II, Ulster University, Belfast, Northern Ireland, 2–3 June 2016).

27. For example, see Price “What Is Reproductive Justice?”

28. Dionne P. Stephens, Vrushali Patil, and Tami L. Thomas, “STI Prevention and Control for Women: A Reproductive-Justice Approach to Understanding Global Women’s Experiences,” in *Reproductive Justice: A Global Concern*, ed. Joan C. Chrisler (Santa Barbara, CA: Praeger, 2012), 117–44; Sundstrom et al., “Reproductive-Justice Approach.”

related cancers.²⁹ Research also suggests that women negotiate and sometimes resist cervical-cancer screening. Therefore, we cannot underestimate the importance of ethical communication that provides a complete understanding of the risks and benefits of screening and overcomes medical control of women's bodies.³⁰ Effectively countering antivaccination movements requires communication that moves beyond essentializing women to their reproductive function and reconceptualizes normative, "natural" processes by countering the false duality between "natural" and "technological" applied to vaccination, screening, and treatment.³¹ An analysis of the cervical-cancer prevention crisis uncovers historical, religious, and cultural contexts for reproductive justice and women's health in Ireland. This intersectional analysis improves understandings of health inequities, particularly among marginalized women, such as Traveller, refugee, and asylum-seeking women.

TRUTH TELLING

In 2007 the United Nations described a "right to truth" for individuals, societies, and nations. Over the last half-century truth telling in the form of truth-and-reconciliation commissions has been recognized as a central feature of a postwar movement to secure justice and extend reparations.³² Beyond that specific postwar context, truth

29. Prabal De and Henna Budhwani, "Human Papillomavirus (HPV) Vaccine Initiation in Minority Americans," *Public Health* 144 (2017): 86–91; Amy M. Burdette et al., "Race-Specific Trends in HPV Vaccinations and Provider Recommendations: Persistent Disparities or Social Progress?" *Public Health* 142 (2017): 167–76; Sharon M. Bond et al., "Racial and Ethnic Group Knowledge, Perceptions, and Behaviors about Human Papillomavirus, Human Papillomavirus Vaccination, and Cervical Cancer among Adolescent Females," *Journal of Pediatric Adolescent Gynecology* 29:5 (2016): 429–35.

30. Judith Bush, "'It's Just Part of Being a Woman': Cervical Screening, the Body, and Femininity," *Social Science & Medicine* 50:3 (2000): 429–44.

31. Sundstrom et al., "Reproductive-Justice Approach."

32. United Nations, *Rights to the Truth: Report of the Office of the Higher Commissioner for Human Rights*, (UN Doc. A/HRC/5/7, 7 June 2007); Hala Bassel, "Acts of Truth Telling and Testimony in the Conceptualisation of Reparations in Post-Conflict Peru," *Global Society* 34:1 (2020): 84–98; Alison Crosby and M. Brinton Lykes, "Mayan Women Survivors Speak: The Gendered Relations of Truth Telling in Postwar Guatemala," *International Journal of Transitional Justice* 5:3 (2011): 456–76; Margaret Urban Walker, "Truth Telling as Reparations," *Metaphilosophy* 41:4 (2010): 525–45.

telling offers a mechanism to document and condemn violations of human rights, which may or may not include judicial action.³³ According to Bassel, truth telling among the victims of enforced sterilizations in Peru, for example, served as a nonviolent method of historical justice that protected victims' right to the truth as a form of resistance and created the possibility of reparation.³⁴ Walker argued that truth telling by victims of injustice is a kind of reparation, though it is unlikely to be sufficient by itself.³⁵

In most cases truth telling in response to violations of human rights is initiated by the state. However, Crosby and Lykes have investigated cases of truth telling introduced by civil society, and specifically those that featured accountability through recognition of women's voices, the avoidance of reifying or essentializing women's experiences, and affirmation of local women's meaning-making.³⁶ It is this approach—especially when amplified through the use of social media—that made truth telling transformative in the Irish context. For example, when Vicky Phelan refused to sign a confidentiality clause, she gave power to women's voices and stories, refusing to be silenced. When other women shared their experiences with cervical cancer on social media, they controlled their stories and demanded transparency and accountability. Gilmore argues that social media has democratized truth telling, allowing new credible speakers to emerge as power shifts. Her analysis of truth telling in the #MeToo movement revealed instances of “so much pain, carried over a lifetime, exacerbated by silencing, that poured into the public square.”³⁷ Social media offers a platform to cocreate health and illness narratives and share everyday lived experiences.³⁸ Online narratives enable individuals to see themselves in the stories of others, creating emo-

33. Emily Rosser, “The Messy Practice of Building Women’s Human Rights: Truth-Telling and Sexual Violence in Guatemala,” *Latin American Policy* 6:1 (2015): 68–88.

34. Bassel, “Acts of Truth Telling.”

35. Walker, “Truth Telling.”

36. Crosby and Lykes, “Mayan Women Survivors.”

37. Leigh Gilmore, “He Said/She Said: Truth-Telling and #MeToo,” *FORUM: University of Edinburgh Postgraduate Journal of Culture & the Arts* 25 (2017): 2–3.

38. B. F. Sharf, “Observations from the Outside In: Narratives of Illness, Healing, and Mortality in Everyday Life,” *Journal of Applied Communication Research* 37:2 (2009): 132–39; Beth Sundstrom et al., “Voices of the ‘99 Percent’: The Role of Online Narrative to Improve Health Care,” *Permanente Journal* 20:4 (2016): 49–55.

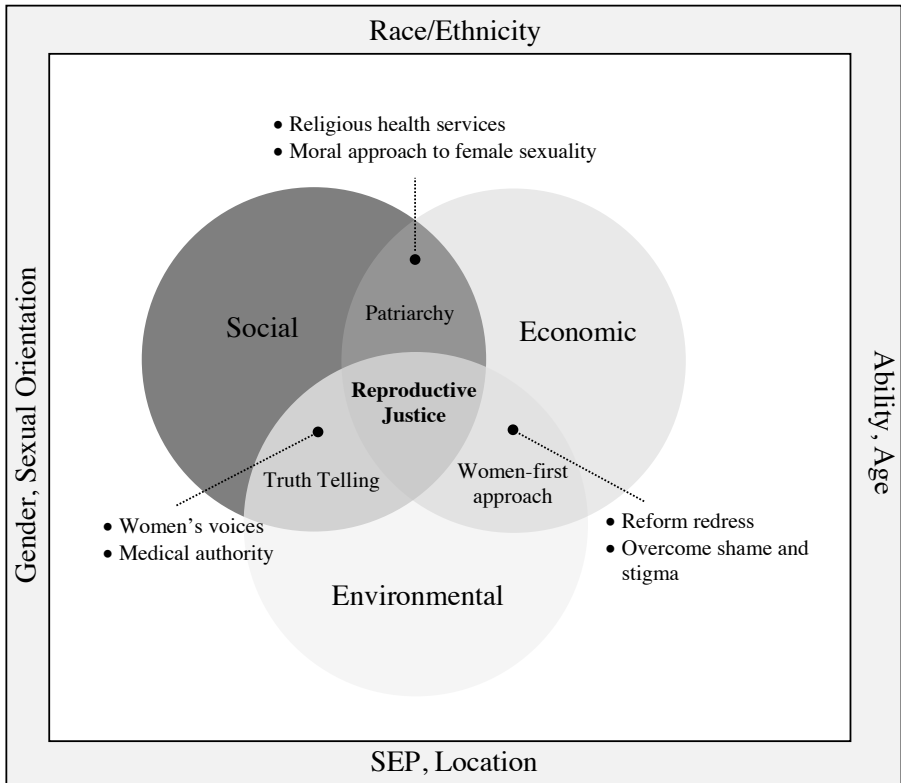


FIGURE 1. A reproductive-justice approach to understanding the cervical-cancer prevention crisis in Ireland. Adapted from Sundstrom et al., “Reproductive-Justice Approach,” and Beth Sundstrom et al., “Moving Oral Contraceptives over the Counter: Theory-Based Formative Research to Design Communication Strategy,” *Journal of Health Communication* 25:4 (2020): 313–22.

tional and intellectual engagement.³⁹ In Ireland social media also provided an anonymous, decentralized platform, which created new opportunities for such marginalized groups as Traveller, refugee, and asylum-seeking women who may not have always been welcomed by mainstream movements to engage in truth telling.⁴⁰

39. Thomas K. Houston et al., “The Art and Science of Patient Storytelling—Harnessing Narrative Communications for Behavioral Interventions: The ACCE Project,” *Journal of Health Communication* 16:7 (2011): 686–97.

40. Sonja Vivienne and Jean Burgess, “The Digital Storyteller’s Stage: Queer Everyday Activists Negotiating Privacy and Publicness,” *Journal of Broadcast Electronic Media* 56:3 (2012): 362–77.

RESULTS

This analysis examines Ireland's cervical-cancer prevention crisis as it played out through two events, the CervicalCheck cancer scandal and the HPV-vaccination-misinformation campaign. I examine how the CervicalCheck scandal inspired women to confront a legacy of shame and silence around women's bodies and health, and how truth telling empowered women to challenge systems of inequality. My analysis of the HPV-vaccination-misinformation campaign shows how the HPV Vaccination Alliance successfully countered HPV-vaccine hesitancy by advocating for ethical communication, including truth telling, in order to protect and advance the position of individuals in vulnerable situations. Figure 1 summarizes these findings by applying a reproductive-justice approach to understanding the cervical-cancer-prevention crisis in Ireland. Findings are contextualized through social, economic, and environmental concepts, including gender, sexual orientation, race, ethnicity, socioeconomic position, immigration status, age, and ability.

CERVICALCHECK CANCER SCANDAL: CONFRONTING SHAME AND SILENCE

In the mid-nineteenth century doctors noticed that cervical cancer was rare among Catholic nuns but fairly common among other women. Although this observation would eventually lead to the first vaccine for cancer, it also stigmatized cervical cancer by linking it to sexual activity: "Prostitutes had a relatively high risk of contracting the disease, married women in town had a moderate risk, and the celibate nuns (with the unfortunate, presumably rare, exceptions) were spared. This epidemiological profile strongly suggested that a sexually transmitted agent played an important role in the development of cervical cancer."⁴¹ Stigmatizing women's sexuality and shaming women for negative health outcomes emerged as a central theme in the 2018 Scally Report. Scally described what he considered "one of the most disturbing accounts" of a disclosure meeting in which the close relatives of a deceased woman were told that "nuns don't get cervical cancer."⁴²

41. Daniel DiMaio, "Nuns, Warts, Viruses, and Cancer," *Yale Journal of Biology and Medicine* 88:2 (2015): 127.

42. Scally, "Scoping Inquiry."

These types of occurrences were typical of a system that inculcated a gendered shame in its patients. According to one of the experts in women's health in Ireland whom I interviewed, "the same thing wouldn't have happened if it were men's health we were talking about, the way a lot of those women were spoken to by consultants and medical professionals was very gendered and it seemed to wrap up a lot of negative issues and ideas around women's sexuality, it was a medical issue that seemed to have a moral tone to it, which it shouldn't have." The health-care system, government, and media added to this stigma and shame by attempting to silence the women impacted by the CervicalCheck scandal, a form of "disciplining device" as identified by Fischer that operated "through structures of oppression such as gender, but also class, race, ethnicity, sexuality, nationality, and related intersectional categories."⁴³ In an interview an Irish legal expert described the disciplining device in the cervical-cancer crisis as conveying the message that "it would be better if victims and women in particular just shut up."

Women affected by the crisis, however, forced acknowledgment of the history of shame and silence in Ireland, drawing on this interdiction to spur them toward truth telling and action. An interviewee provided an example of how this perspective manifested itself in Irish culture, noting that "a number of op-eds in papers suggested that these women alone were going to bring down the CervicalCheck system and were going to destroy health care for other women." In response to the CervicalCheck crisis, Migrants and Ethnic Minorities for Reproductive Justice (MERJ), a group of migrants and ethnic minorities living in Ireland who are fighting for reproductive justice, posted on Facebook, "This is outrageous! It is also important to note that migrants without PPS numbers are not entitled to smear tests under the CervicalCheck system. We must demand reproductive justice for EVERYONE in Ireland."⁴⁴ The women who brought attention to the CervicalCheck scandal faced scrutiny and public attacks while seeking to improve health care for all women, but they persisted in their truth telling.

In the 2018 Scally report many individuals credited Phelan with

43. Clara Fischer, "Gender and the Politics of Shame: A Twenty-First Century Feminist Shame Theory," *Hypatia* 33:3 (2018): 371.

44. MERJ (@MERJIreland), Facebook, 29 April 2018, 7:37 a.m.

highlighting the failures of CervicalCheck. Phelan was diagnosed with cervical cancer in 2014, and a routine audit found that her 2011 pap test was incorrect; however, she was not informed about the audit until 2017. Scally described the widespread nondisclosure of standard CervicalCheck audits as a “whole-system failure.” MERJ similarly called out systemic, widespread failures in the system’s response to the CervicalCheck scandal, posting, “This is why we need #ReproductiveJustice.”⁴⁵ In July 2019 Professor Brian MacCraith, the president of Dublin City University, released an independent review of CervicalCheck that found that more than 800 women and their physicians had not been informed about the results of their screening test owing to IT failings and human error. The report found a lack of clear responsibilities and authority within the CervicalCheck system. MacCraith recommended that the HSE adopt a “women-first” approach to focus on providing continuous information to women, improving customer-relationship management and building trust.⁴⁶ Succeeding in a women-first approach, however, will require a commitment to dialogic-communication ethics, including truth telling, which can repair, reconcile, and protect communities and cultures after disruption and conflict.⁴⁷

Finally, in 2019 the UK Royal College of Obstetricians and Gynecologists (RCOG) conducted an external, independent review to better understand how many samples were misread. An expert panel reviewed 1,038 cancer slides and determined that 159 women could have been diagnosed earlier. Among those 159 cases, at least 12 women have died. At the time the report was released, there were more than 100 legal cases filed against CervicalCheck. As a result of the uncertainty, women were offered a free repeat test; however, they often waited more than twenty weeks to receive their results. In an interview on RTÉ Radio One’s *Morning Ireland*, Dr. Nóirín Russell emphasized that “it’s really important not to underestimate how

45. MERJ (@MERJIreland), Facebook, 27 April 2018, 5:39 a.m.

46. Brian MacCraith, *Independent Rapid Review of Specific Issues in the CervicalCheck Screening Programme*, 2 Aug. 2019, <https://www.hse.ie/eng/services/publications/corporate/independent-rapid-review-of-specific-issues-in-the-cervical-check-screening-programme.pdf>, archived at <https://perma.cc/QG96-8CSW>.

47. Ronald C. Arnett and François Cooren, *Dialogic Ethics* (Amsterdam: John Benjamins, 2018).

stressful it is for women waiting for an appointment that we're unable to tell them when it will be."⁴⁸

Despite the flaws in the system, health providers emphasize that they believe in cervical-cancer screening and its ability to prevent cancer. Brendan O'Shea, a general practitioner in County Kildare and a member of the council at the Irish College of General Practitioners, asserts that "regarding CervicalCheck, the science of this says we must match the courage and trust of thousands of women who attend practices for cervical screening every day and commit to do it better, while carefully remembering those whom the system has failed." According to an expert from a national women's health organization in Ireland, "if you look at [CervicalCheck's] success at reducing cancer over a number of years, it's really impressive. . . . I think what needs to happen now is we need to restore the reputation of CervicalCheck. I think it's very important and has had a really positive impact."⁴⁹

In what activists described as a "watershed moment," on 22 October 2019 taoiseach Leo Varadkar apologized for the CervicalCheck failures on behalf of the government.⁵⁰ His statement asserted:

On behalf of the government and the state, I am sorry it happened. And I apologize to all those hurt or wronged. And we now vow to make sure it never happens to anyone else again. . . . We are sorry for the failures of clinical governance, sorry for the failures of leadership and management, sorry for the failure to tell the whole truth and to do so in a timely manner, sorry for the humiliation, the disrespect, and deceit.⁵¹

Advocates described the apology as "an acknowledgement from the core of our government that our health-care system was not patient-centered."⁵² In the years since the apology, the government has worked to implement new policies to address the failings of CervicalCheck.

48. Liz Farsaci, "Increase in Abuse on CervicalCheck Staff; Delays and Anxiety Caused 'Perfect Storm.'" *Daily Mirror*, 6 Dec. 2019.

49. Brendan O'Shea, "Patients—and Medics—Need to See a Quick and Honest Response When Things Go Seriously Wrong," *Irish Independent*, 4 Dec. 2019.

50. Aine McMahon, "Women and Families Affected by CervicalCheck Hail Apology as 'Watershed Moment,'" *Press Association Newswire: Ireland*, 22 Oct. 2019.

51. "Taoiseach's CervicalCheck Apology in Full," *RTÉ News*, 22 Oct. 2019.

52. McMahon, "Women and Families."

Minister for health Simon Harris said that CervicalCheck had caused “massive pain and hurt to people right across the country,” and worked to release a new patient-safety bill that ensures mandatory disclosure to patients.⁵³ Since March 2020 CervicalCheck now provides HPV cervical screening, which offers additional accuracy.

REVEALING TRUTH TELLING

Through truth telling women revealed and confronted systems of inequality that perpetuate shame and stigma around women’s bodies and health. In the Irish context truth telling and activism have been necessary to spur the state to take action through redress schemes. This analysis shows that the CervicalCheck scandal gained national recognition because women refused to be silent. As an expert from a national women’s organization in Ireland stated, “What was essential to [the CervicalCheck] issue was women talking about their experiences and being unwilling to sign an NDA and talking about the treatment they had. The inquiry that was commissioned into the government was saying that women are always asking, Why is this always happening to women in Ireland? And [Scally] named issues like patriarchy in the health service.” Experts and activists positioned the CervicalCheck scandal as part of a history of women’s rights abuses, such as the Magdalen laundries, mother-and-baby homes, symphysiotomies, and the Eighth Amendment. Fischer argues that “shame becomes internalized, forming part of gendered, racialized, and classed subjectivities.”⁵⁴ In the cervical-cancer prevention crisis, Irish women’s voices and narratives exposed the consequences of perpetuating shame and stigma around women’s bodies.

Historically, the government has sought to remedy wrongs by compensating victims through redress schemes. An expert from a national women’s organization in Ireland reminds us that

we’ve seen in Ireland time and time again with the Magdalen women, children in industrial schools, the state did once have a duty of care,

53. “Simon Harris: CervicalCheck Staff ‘Subjected to Abuse,’” *Irish Examiner*, 6 Dec. 2019.

54. Clara Fischer, “Gender, Nation, and the Politics of Shame: Magdalen Laundries and the Institutionalization of Feminine Transgression in Modern Ireland,” *Signs: Journal of Women in Culture and Society* 41:4 (2016): 839.

and unfortunately it does take a lot of fighting from the survivors and their supporters to see redress schemes. I don't think Ireland has gotten redress right yet, and here's an opportunity where we have another chance to do that, and we're not taking it. I think what people want and what so many women who were affected by the Cervical-Check scandal want is for the screening service itself to be something people can stand over, to be trustworthy. That's a big responsibility and something the government can surely do [to] make sure the system is working for women.

Scholars argue that a fundamental prerequisite to trust is honesty. A legal expert explains:

I think before we apply any new redress schemes, we need to have a human-rights review of the habits of redress that have been developed, finessed over time by the Department of Justice and the state. We have ample evidence now to say people who participate in those schemes feel bullied, marginalized, shamed, and often regret that they accepted the redress scheme. . . . Most people place more emphasis on the importance of truth telling. I think truth telling is an important aspect of reproductive justice because in international human-rights law, one of the key human-rights guarantees is non-repetition, and I don't think you can guarantee nonrepetition if you don't know what you did. If you don't investigate the patterns of abuse that we were complicit in [in] the past, you can't guarantee something similar won't happen in the future.

Attempts at redress have been limited by systems of social inequality that restrict women's rights. CervicalCheck shows that women's bodies and health will continue to be marginalized in a patriarchal system. In this context redress offers limited benefits to the women impacted by CervicalCheck and fails to prevent future harm. A reproductive-justice approach to reforming redress schemes must be grounded in human rights and a commitment to nonrepetition to avoid further victimization.

Moreover, redress schemes must include truth telling, which is particularly important because attempts at redress have attempted to silence women through nondisclosure, confidentiality clauses, sealing of records, and other methods. Scholars argue that truth telling and resulting policies must be understood in the social, political, and historical context of the injustice.⁵⁵ Truth telling is a form of resis-

55. Rosser, "Messy Practice"; Walker, "Truth Telling."

tance and has the potential to initiate a broader societal dialogue to define and understand human rights.⁵⁶ In Ireland social media provided a platform for women to share their narratives of health and illness in greater numbers than ever before. For the first time in Ireland women's ways of knowing and their lived bodily experiences became central features in the national discourse. Irish women with a public platform, such as those with terminal cancer, as well as large numbers of anonymous women, shared their stories to overcome the shame and stigma historically linked to women's bodies and health. Although testimonials remain vulnerable to long-standing biases and prejudices,⁵⁷ the scale and authenticity of Irish truth telling succeeded in changing the conversation around women's health. Rosser emphasizes that while advances in law are important, truth telling, activists, and advocacy remain crucial components of establishing women's human rights.⁵⁸ The commitment of advocates over decades has been essential to providing a space for women to speak out today and spurring the state to take action through redress schemes.

In addition to the social and legal issues advanced through truth telling, women's stories have raised cervical cancer to the national spotlight as an important health issue. According to one interviewee, an expert from a national women's health organization, "One unintended consequence of speaking out is that you can actually see that people have a name, there's someone to identify with the devastating effects cervical cancer can have. It's probably not the way you want to do health-promotion campaigns, but the importance of regular screening has been highlighted through that controversy." An expert from a different national women's organization concurred: "In terms of uptake, there's a positive impact because people are hearing about cervical cancer, they're hearing from women speaking about how it's impacted their lives. This is not the way to increase uptake of screening, but it has been [increasing]." The women impacted by the CervicalCheck scandal shared their stories to change the narrative around cervical cancer, personalize the issue, and save the lives of other women.

The CervicalCheck scandal bolstered a national commitment

56. Rosser, "Messy Practice."

57. Gilmore, "He Said/She Said."

58. Rosser, "Messy Practice."

to cervical-cancer screening and improved health care for women. According to Lorraine Walsh, who was impacted by the CervicalCheck scandal and formerly served on the CervicalCheck steering committee: “What must follow is that those in power to do so will work to establish governance structures, the oversight, the management capacity, and the quality-assurance checks to ensure these failures never happen again. . . . Our hope now is for a time in Ireland when no woman will ever again have cause to doubt the availability or the quality of the health care they receive from the state.”⁵⁹ Indeed, women’s commitment to one another and to building a better future was highlighted once again through this crisis. As one interviewee remarked, “Women are kind and generous in thinking about women coming after them, and what they want is for the system to be safe. I’ve been really impressed by people who are advocating for younger women who won’t be affected in the same way they were, but who feel the screening services are really important. So the government needs to support the women who have been affected, but it also needs to build a trusted system again.” The CervicalCheck scandal is the latest in a series of women’s health scandals that have confronted Ireland’s patriarchal system. By raising their voices, women who spoke out about cervical cancer became part of a legacy of truth telling.

HPV VACCINATION MISINFORMATION CAMPAIGN: ADVOCATING FOR ETHICAL COMMUNICATION

In 2010 Ireland introduced a school-based HPV-vaccination program for girls aged 12–13, and by 2015 nearly eighty-seven percent of girls had completed the vaccination series. In the same year antivaccine groups with international support distributed misinformation in Ireland against HPV vaccination through social media as well as local and national media, and they lobbied politicians against its use. The misinformation campaign broadcast the so-called documentary *Cervical Cancer Vaccine—Is It Safe?* on national television. The film featured parents and teens describing side effects, injuries, and long-term health issues falsely linked to the HPV vaccine. Footage in the film that had appeared in a similar broadcast in Denmark made it clear

59. McMahon, “Women and Families.”

that it was a part of a coordinated international antivaccine movement that may have started as a series of viral videos on YouTube before going on to devastate vaccine confidence in Japan, Denmark, Colombia, and Ireland.⁶⁰ Indeed, by the time it arrived in Ireland, the HPV-vaccine-hesitancy crisis had already led to panic in Japan, causing vaccination rates to drop from approximately 70 percent to less than 1 percent,⁶¹ and in Denmark, where rates dropped from 79 percent to 17 percent.⁶² Experts estimate that the HPV-vaccine-misinformation campaign in Japan cost 5,000 avoidable deaths from cervical cancer.⁶³ The U.S. Healthy People guidelines target eighty-percent vaccination rates to reduce or eliminate six HPV-related cancers. Ireland had in fact met this target, but the misinformation campaign undermined the maintenance of those rates. As Zimet and Osazuwa-Peters note, “unwarranted fears about HPV vaccine and the proliferation of misinformation, particularly via social media, have proven to be significant and widespread obstacles to achieving and maintaining high vaccination rates.”⁶⁴ By 2017 uptake of the first dose of the HPV vaccine decreased to less than forty percent of girls, fueled by the campaign’s ability to raise parental concerns about vaccine safety.

This campaign, with its effects on vaccine rates, was no less than “fearmongering,” as one interviewed expert from a national women’s health organization described it. An Irish physician added, “I couldn’t believe that I was hearing such dangerous falsehoods.”⁶⁵ Furthermore, the misinformation campaign perpetuated stigma and shame around women’s bodies and sexuality that “cannot easily be disaggregated from long-standing myths and fears about female

60. Daniel Artus, Heidi Larson, and Patty Kostkova, “Role of Social Media in Vaccination Debate about HPV: The VAC Medi+Board Study,” *European Journal of Public Health* 29:4 (2019): 250–51; Simms et al., “Impact of HPV.”

61. Sharon J. B. Hanley et al., “HPV Vaccination Crisis in Japan,” *The Lancet* 385:9987 (2015): 2571.

62. David Robert Grimes, “Terminally Ill at 25 and Fighting Fake News on Vaccines,” *New York Times*, 11 Dec. 2019, <https://www.nytimes.com/2019/12/11/opinion/anti-vaccine-HPV.html>.

63. Simms et al., “Impact of HPV.”

64. Gregory D. Zimet and Nosayaba Osazuwa-Peters, “There’s Much Yet to Be Done: Diverse Perspectives on HPV Vaccination,” *Human Vaccines & Immunotherapeutics* 15:7–8 (2019): 1459.

65. Grimes, “Terminally Ill.”

sexuality.”⁶⁶ As a result, the HPV vaccination crisis revealed the biological, economic, social, and political systems that shape women’s access to and decision-making about health. In part the misinformation campaign succeeded initially because of the complicated intersections of gender, race, ethnicity, socioeconomic position, immigration status, ability, sexual orientation, and age as sources of reproductive oppression. Although HPV is an ubiquitous virus, its definition as an STI led to the social construction of cervical cancer as a stigmatized disease. Social norms impact understandings of cervical cancer (and by extension HPV) that are tied to identity and relational meanings. In particular, cervical cancer and HPV are perceived as diseases of the “other” and are linked to what it means to be “responsible,” particularly as an adolescent or young woman.⁶⁷

The misinformation campaign relied on emotional manipulation targeted at the parents of young girls, as in this example noted by Grimes:

You’ll often see a scare story that says—particularly a teenage girl—has had an adverse effect to this vaccination. And it’ll be delivered in a very frightening way that captures your attention. It doesn’t matter that the stories lack any veracity. What matters is they scare us, and in scaring us, we remember them. And in remembering them, we afford them more weight than they deserve. And so starts a vicious cycle. This explains why lies about the HPV vaccine were able to do so much damage in so many countries.⁶⁸

Since mothers overwhelmingly make vaccination decisions for their children, the decision to choose the HPV vaccine for their daughters is perceived as being related to what it means to be a good mother. Scholars also argue that antivaccination campaigns take advantage of scientific uncertainty and lack of knowledge: “What from a scientific and public health viewpoint appears as a medical breakthrough—the creation of a drug that protects against cervical and other forms of

66. Gave Mythen and Mads P. Sørensen, “Unscrambling Risk, Contesting Expertise: The Case of the Human Papillomavirus (HPV) Vaccine,” in *Ageing, the Body, and the Gender Regime: Health, Illness, and Disease across the Life Course*, ed. Susan Pickard and Jude Robinson (London: Routledge, 2019), 38–52.

67. Sundstrom et al., “Reproductive-Justice Approach.”

68. Grimes, “Terminally Ill.”

cancer—becomes translated into a tough choice that parents must make regarding their children’s future health.”⁶⁹ In the context of these misinformation campaigns parents continued striving to make the best decision for their children.

To combat the misinformation campaign, over thirty-five Irish organizations, charities, and public institutions joined together in 2017 to form the HPV Vaccination Alliance. According to a member of the alliance, the initiative achieved success by broadening the base of people who advocated for the vaccine, including parents:

We’re a pretty small country and community, and there are a lot of people coalesced around this issue, so I think that was one of the ways we were able to combat what [the misinformation campaign] was saying. There has to be quite a lot of training with the media, not that you can train the media, but talking about the evidence, actual numbers, and new voices available to speak on the evidence. It was very much led by the cancer community, but they were really good at drawing on all these other groups who had other pieces of experience to talk about. Like so many countries, we had issues around the MMR vaccine as well, so people had experience on how to combat the antivaxxers.

The alliance promoted HPV vaccination through a communication campaign incorporating social and traditional media as well as personal testimonies. Initially, health, children, and women’s groups signed a “contract against cancer” to publicly declare a commitment against misinformation. The alliance spearheaded a #HPVVAX-FACTS campaign to provide fact-based information about the HPV vaccine and HPV-caused cancers. They also created a series of videos with parents and cervical-cancer survivors talking about their choice to vaccinate.

In Ireland HPV vaccination has started to increase again, reaching approximately 62 percent in 2018 and 75 percent in 2019.⁷⁰ According to Simms et al., “The events relating to HPV vaccination in Ireland and Denmark show that it is possible to reverse rapid declines

69. Mythen and Sørensen, “Unscrambling Risk.”

70. Brenda Corcoran, Anna Clarke, and Tom Barrett, “Rapid Response to HPV Vaccination Crisis in Ireland,” *The Lancet* 391:19135 (2018): 2103; Artus, Larson, and Kostkova, “Role of Social Media.”

in HPV vaccine coverage due to vaccine hesitancy and successfully address safety concerns reported in the media. Strong support from government is required and is most effective when there is cooperation across multiple sectors.”⁷¹ Ireland’s ability to successfully counter HPV vaccine hesitancy depended on ethical communication and support from stakeholders, including partnerships between government and activists.⁷²

Ethical communication must move beyond truthfulness and reliability of information toward beneficence or “the duty to contribute to a better society, to social justice, to the good of the people.”⁷³ In particular, ethical communication aims to protect and advance the position of individuals in vulnerable situations. According to Aznar and Castillo-Martin, ethical communication intends “to give voice to those affected by a situation, and especially those in a situation of vulnerability, because this is the prime way in which they can make their voices heard and improve their situation.”⁷⁴ Scholars identified “hard-hitting personal testimonials” as a key component of the HPV Vaccination Alliance’s communication campaign.⁷⁵ Within this context, Phelan and other women impacted by the CervicalCheck scandal became advocates for HPV vaccination. Laura Brennan, who died from cervical cancer in March 2019, consulted about HPV advocacy for the World Health Organization. She observed that “this illness is devastating and it’s going to take my life, but the good news is there’s a vaccine that you can get that prevents it. HPV caused my cancer. I just wanted parents to know there is an alternative.” Phelan wrote on Twitter, “We have a vaccine that can prevent future generations of women developing cervical cancer. As someone who is terminally ill with this cancer, I urge you to get your children vaccinated. You. Do. Not. Want. This.”⁷⁶

The truth telling that revealed the CervicalCheck scandal became a critical feature of the HPV Vaccination Alliance’s communication

71. Simms et al., “Impact of HPV,” e232.

72. Jamie Horder, “Toll of Vaccine Hesitancy,” *Nature Human Behaviour* 4 (2020): 335; Simms et al., “Impact of HPV.”

73. Hugo Aznar and Marcia Castillo-Martin, “‘Vulnerability’ as the Key Concept of a Communicative Ethics for the 21st Century,” *Media Development* 4 (2018): 18.

74. *Ibid.*, 19.

75. Artus, Larson, and Kostkova, “Role of Social Media.”

76. Vicky Phelan (@PhelanVicky), Twitter, 10 May 2018.

campaign. Experts suggest that these women's voices successfully reached parents:

But in Ireland, what really changed the situation was a woman called Laura Brennan. When Laura was twenty-four, she was diagnosed with cervical cancer, and by the time she was twenty-five, that was metastatic, non-curable. Laura was alarmed that people weren't getting this vaccine that could prevent women from being in the situation that she found herself in. Her campaigning started with a series of advertisements where she talked to parents, directly to them.⁷⁷

In a video titled "Don't Be Swayed by Rumors" that is aimed at parents, Laura discussed her cervical-cancer diagnosis and treatment, sharing that when her cancer returned, there was no treatment that could cure her. She said, "If anything good comes out of this, I would hope parents would get their daughters vaccinated. The vaccine saves lives, it could have saved mine."⁷⁸

The central lesson of the HPV-vaccination-misinformation campaign reflects the crucial need to listen: "It is incumbent on experts involved in medical and scientific risk communication to be alert and sensitive to the side effects of uncertainty and its capacity to generate anxiety."⁷⁹ According to Aznar and Castillo-Martin, ethical communication must "be oriented to make the participation of the people easier, to promote their sense of being a part of the public debate, a part of the social community in dialogue."⁸⁰ The success of the HPV Vaccination Alliance is promising as Ireland works to modernize health care and serve the needs of women. However, the threat has not been completely eradicated: "A combination of hard-hitting personal testimonials, social media, and traditional media promoted the HPV vaccine. Despite this, systematic engagement and supranational strategies are still in the early stages of being formulated. As misleading information spreads through social media and digital networks have undesirable impacts on attitudes to vaccination (and uptake rates), urgent actions are required."⁸¹

77. Grimes, "Terminally Ill."

78. Health Service Executive, "Human Papillomavirus (HPV) Vaccine."

79. Mythen and Sørensen, "Unscrambling Risk."

80. Aznar and Castillo-Martin, "Vulnerability," 19.

81. Luis Saboga-Nunes and Patty Kostkova, "Online Anti-Vaccination Movements: The Role of Social Media in Public-Health Communications," *European Jour-*

CONCLUSION: A WOMEN-FIRST APPROACH

CervicalCheck and the HPV-vaccination-misinformation campaign revealed institutionalized misogyny within Ireland’s government, health-care system, and society. The problem, as one interviewee described it, is that “most of the health services in Ireland have been religious ones, and that has impacted so many services like symphysiotomy and all these areas [so] that a moralistic approach to sexuality has been very clear for women.” In an interview with CNN, Mary McAuliffe, a historian in gender studies at University College Dublin, described how this approach to sexuality has impacted women’s health: “Women’s bodies and the risk to women’s bodies are not [considered] important—and in particular their reproductive bodies and their health care is seen as secondary to maybe money, to power, and to a patriarchal system that has always seen women as second-class citizens.”⁸² Despite a system that has historically devalued women, women continue to engage in storytelling about health, illness, and the body to confront, challenge, and change Ireland’s health-care system.

The 2018 Scally report and the 2019 MacCraith review recommended a women-first approach to health care. In a Twitter thread Phelan responded to these recommendations:

Dr. Scally recommended that the minister of health Simon Harris “give consideration to how women’s health issues can be given more consistent, expert, and committed attention” within our health system. Professor MacCraith has recommended a “women-first” approach. WE NEED TO MAKE THIS HAPPEN.

We need to take women’s health more seriously. Dr. Scally demanded that “more and different attention NEEDS to be paid to women’s health issues.” It is simply not enough to pay lip service to women’s health. We have had enough.⁸³

Cliona Loughnane of the National Women’s Council shared a similar sentiment about what needs to happen next: “We need to put struc-

nal of Public Health 29:4 (2019): 250.

82. Kara Fox, “A Scandal Over Cervical Checks Is a Sign of a Bigger Problem in Ireland,” *CNN*, 5 Oct. 2019, <https://www.cnn.com/2019/10/05/europe/ireland-cervical-check-scandal-intl/index.html>.

83. Vicky Phelan (@PhelanVicky), Twitter, 8 Aug. 2019.

tures in place and the policies in place that react to what women say they need on the ground.”⁸⁴

Listening to women may be the best way to improve health care: “I think what the CervicalCheck scandal showed is that we need as much attention on women’s health, on taking it seriously,” stated one expert on women’s health. In order to take women’s health seriously, the practices that emerge must focus on truth telling as an important aspect of reproductive justice. Ethical communication about cervical screening is a first step toward this goal, according to an expert with a national women’s organization:

The [patient-involvement] panel we’re on is about the information going out to women on cervical screening and about open disclosure and consent, so there’s a real attempt to let women know what screenings can pick up and what screening cannot pick up, what you’re consenting to, and so on. That’s being done in this new modern way of helping health care, and helping get information to patients is providing women with expertise on women’s health.

Ultimately, a women-first approach to health care must be grounded in ethical communication. Indeed, “social communication has to be a way to build an effective community through the communicative participation of the individuals.”⁸⁵

Patriarchy in the health service emerged as a primary cause of the cervical-cancer prevention crisis. The ongoing impact of Ireland’s religious health services was evident in the CervicalCheck scandal and the HPV-vaccination-misinformation campaign. Patriarchy and religious health services impacted the care that women received related to HPV vaccination and cervical-cancer screening by perpetuating a moral approach to female sexuality grounded in myths and fear of women. Women themselves, however, challenged these systems through truth telling. Through advocacy and raising their voices, women contested medical authority. They addressed issues of consent, the right to knowledge about their own bodies, and scientific uncertainty. Finally, as Ireland strives toward a women-first approach to health care, experts argue that reforming redress schemes must be

84. Fox, “Scandal.”

85. Aznar and Castillo-Martin, “Vulnerability,” 19.

grounded in human rights and a commitment to nonrepetition so as to avoid further victimization. Overcoming misogyny will depend on listening to women and addressing shame and stigma around women's bodies.

Although gains have been made, advocates continue to identify flaws in Ireland's commitment to nonrepetition. In October 2020 the CervicalCheck Tribunal was established as an alternative legal mechanism, outside of the courts, to hear and determine claims from the CervicalCheck scandal. The goal is for the tribunal to be expeditious, effective, and less adversarial than the courts. CervicalCheck campaigners, including Phelan, have expressed concerns about the tribunal, including the impact of statutes of limitations and the issue of cancer recurrence. The proposed 2019 Patient Safety Bill, which would provide for open disclosure and mandatory reporting of serious patient-safety incidents, remains stalled in the Dáil in 2021 despite the government confirming its commitment to the legislation. Although truth telling has demonstrably improved cervical-cancer prevention in Ireland, the CervicalCheck Tribunal and Patient Safety Bill provide evidence that challenges to achieving reproductive justice remain.