Speculum: Characterizing the creation, curation, reproduction, and neglect of women's health information on the English language Wikipedia

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Abstract

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Information School | Human Centered Design & Engineering

"The encyclopaedia was traditionally a mirror of the world (a *speculum*)—of how it was, of how it should be."

Andrew Brown, 2011

Wikipedia is one of the most powerful and ubiquitous information sources in our world today. Content from the English language Wikipedia—the oldest and largest of more than 300 language Wikipedias—populates a range of information systems, topping Google search results and shaping the responses of intelligent assistants like Siri and Alexa. In recent years, the online encyclopedia has also become a prominent source of health information for both patients and practitioners. Wikipedia, however, is not without its problems. Although Wikipedia purports to be the encyclopedia "anyone can edit," as Ford & Wajcman observe, "not everyone does" (2017). By best counts, more than 80% of Wikipedians are men

(Hill & Shaw, 2013). This demographic skew in participation has come to be known as the *gender gap*. The gender gap in participation has led researchers and Wikipedians alike to ask if who edits Wikipedia results in related gaps in content. Given what we know about Wikipedia's gender gap, what does the encyclopedia have to say about women's health? Who is creating, curating, and controlling women's health information on the English language Wikipedia? Does it matter? What else might matter? In my dissertation, I adapt object biography—a material culture practice used in anthropology—to reconstruct the life-history of a selection of women's health articles on the English language Wikipedia (*n*=5). Drawing from article revision histories, talk page discussions, trace data, interviews with editors (*n*=15), and five years of ethnographic research, I write the biography of each one of these articles, noting how they have grown, been neglected, become boundary objects for different communities (e.g., editors, readers, medical practitioners, laypeople), sparked debates about how scientific knowledge is reproduced, and complicated assumptions about the relationships between participatory gaps and content gaps. The contributions of this work are threefold: (1) by being the first study to explicitly interrogate women's health information on the English language Wikipedia, this work makes a clear empirical contribution; (2) by adapting object biography to tell the life-history of digital objects, this work makes a methodological contribution to information science; (3) finally, by interrogating assumptions about the relationships between participatory gaps and content gaps in user-generated content systems like Wikipedia and by providing empirical evidence that these relationships are more nuanced and complicated than prior work suggests, this dissertation makes a contribution to future social computing research by providing a unique lens through which we might study these relationships. This work also has broader implications for the field of information science, particularly health informatics, given the rise of Wikipedia's reach and influence and the pervasive medicalization of women's health it perpetuates.

This dissertation is dedicated to my nieces, Maiya and MeiLin.

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You've traveled this far on the back of every mistake,
ridden in dark-eyed and morose but calm as a house
after the TV set has been pitched out the upstairs
window. Harmless as a broken ax. Emptied
of expectation. Relax. Don't bother remembering any of it.
Let's stop here, under the lit sign
on the corner, and watch all the people walk by.

Dorianne Laux, 2012

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List of abbreviations and acronyms

Abbreviation	Term
ACM	Association for Computing Machinery
BBC	British Broadcasting Company
CBD	Cannabidiol
CSCW	Computer-supported cooperative work
EN	English (i.e., the English language Wikipedia)
FDA	U.S. Food and Drug Administration
HCI	Human-computer interaction
HPV	Human papillomavirus virus
HSD	Human Subjects Division
ICD	International Statistical Classification of Diseases and Related Health Problems
IRB	Institutional Review Board
IRC	Internet relay chat
MeSH	Medical Subject Headings
NPOV	Neutral point of view
OB-GYN	Obstetrics and Gynecology
PHP	Hypertext Preprocessor
STS	Science and technology studies
THC	Tetrahydrocannabinol
UGC	User-generated content
UNU-MERIT	United Nations University Maastricht Economic and Social Research Institute on Innovation and Technology
URL	Uniform Resource Locator
WHM	Women’s health movement
WMF	Wikimedia Foundation (or the Foundation)
WP	WikiProject
WP WH	WikiProject Women’s Health

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Preface

Drawing a simple or clear boundary around what counts as "women's health" is, for all intents and purposes, impossible. As interviewee Henry shared when describing how Wikipedia's Translation Task Force makes decisions about which articles to translate from English to other languages, what counts as "women's health" is highly contextual:

> *One the articles we're looking at translating is the article on burns, and, you know, from a Western point of view, it might seem unusual why women should be—or why they might have more burns, or why it would be a women's health topic. But if one looks at Africa, one looks at Asia, women do most of the cooking. Women wear long dresses in much of the world, and those dresses catch fire because people are cooking with open flames. So, burns are more of a women's health topic—more of a women's health issue in much of the developing world than it is in the West. So, you know, with respect to the translation project, we're viewing women's health related topics as being fairly broad in scope rather than just being sex and pregnancy related.*

Limiting the category—in any language or geographical setting—to some narrow idea of women's *reproductive health* does not help either. While it may be true health issues relative to pregnancy and breastfeeding are often considered squarely matters of "women's health," it is also true some men (e.g., transgender men) and nonbinary people can also experience pregnancy and breastfeed (in some cases, this is referred to as "chestfeeding"). Additionally, some women may not be able to conceive or become pregnant, but nonetheless may be able to breastfeed (e.g., when transgender women adjust their hormone therapy to facilitate the production of milk).

Similarly, appeals to *chromosomal sex* are also limited. Despite the utility of reference to chromosomal sex in medical contexts, few people actually know or actively relate to their gender in terms of XX or XY. Moreover, chromosomal arrangements are not limited to an XX/XY binary, from *Triple X syndrome* (XXX) to *Klinefelter syndrome* (XXY) to *Turner syndrome* (X0) to intersex variations that generate other arrangements of chromosomes, primary and secondary sex characteristics, and hormones—some of which may be socially or culturally read as "woman" or "female"—it is clear an appeal to sex chromosomes *alone* will not exhaust the issues or populations relevant to "women's health."[1]

So, while issues typically referred to as *women's reproductive health* may correlate heavily with particular chromosomal arrangements or reproductive abilities, they are importantly not limited to them—nor are all possible reproductive health issues relevant to all women at all times or in the same way. Additionally, I recognize there are health issues that may not typically fall under the rubric of "women's health" but may, in fact, become women's health concerns by virtue of effecting women as a matter of circumstance (as with certain transition-specific or other health issues impacting transgender women) or cultural context (as with the burn example above).

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[1] A distinction between "chromosomal sex" and "gender identity" has, in recent years, been leveraged by social and political groups who have sought to exclude or severely curtain the ability of transgender people (specifically transgender women) from public life (e.g., trans-excluding feminist groups or conservative "bathroom bills" that aim to make "chromosomal sex" a condition for use of particular facilities like bathrooms and locker rooms). Another reason, then, for avoiding the reduction of women's health issues to chromosomal sex—beyond the classificatory difficulties described above—is a political one. I do not want this dissertation work to participate in a movement that attempts to marginalize or ostracize transgender people and, in particular, transgender women.

Finally, women's health issues may also be, at times, a concern for caregivers or others who are also not themselves women. Fathers, uncles, brothers, husbands or non-binary partners, and family members may seek out information about women's health when it impacts women in their lives. Additionally, it is currently the case that men work in information-intensive professions like journalism or education that may, at times, require them to seek out health information associated with women. In this sense, women's health is important well beyond the typically cited "half the world's population" who are nominally women—rather, *women's health issues are everyone's issues*.

Recognizing all of the above, I will, for present purposes in this dissertation work, use the term "women's health" to refer to those health concerns that are—historically and/or by convention—typically associated with women, though they may not in practice be exclusive to women. Further, many of my specific case examples concern reproductive organs and processes typically associated with cisgender women. However, I do not intend them as exhaustive or exclusive of those issues or concerns that might be termed "women's health." Rather, it is my fervent hope that the questions of knowledge production I raise and the methods I employ may prove useful for ultimately exploring a wider range of health information issues, including women's health, trans health, global health, and beyond.[2]

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[2] I am grateful to Anna Lauren Hoffmann who thought through this framing, provided words where mine failed, and helped to make this dissertation work more expansive and generative.

Chapter 1: Introduction

Introduction

> *Sosi was 31 when Yasmin was born. Her friends joked she was too old to get knocked up, but there she was: knocked up. Yasmin's father had been an acquaintance at best. He and Sosi had met on a dating app they were beta testing. He was doing it because he knew the developer; she was doing it for some extra cash and because she was bored and restless. He'd message her occasionally, and they'd trade criticisms of the app. He seemed lonely and bored, like Sosi. They exchanged phone numbers and then met for coffee. He looked older in person and spent the entire time talking about his failed marriages. There were two of them. Sosi thought he was probably good in bed but not really her type.*
>
> *A few months passed from coffee to dim sum. He brought a friend. Dim sum made more sense with more people. But after dim sum, he suggested they catch a movie, just the two of them. They stopped by his place first, and he kissed her mid-sentence. He was surprisingly bad at kissing. Sosi thought about stopping, but she thought maybe he'd improve. He didn't. From start to finish, his movements and sounds and eager intentions were awkward. She wanted to spare his feelings. She wanted it to be over. And then it was. He fell asleep on his stomach, she gathered her things, he mumbled something, she said nothing, and she left.*
>
> *She remembers walking up a long hill to her car parked under some trees. It was a quiet night. She stopped on the sidewalk and looked up, watching the leaves move. She relaxed her shoulders, sighed, and stood still. It wasn't until she was driving home that she remembered she was ovulating. She couldn't remember if he had removed the condom he was wearing. She remembered it being there and then not being there.*
>
> *Later Sosi learned the morning-after pill prevents ovulation, not fertilization. After the first test, after the feeling of free falling that wouldn't stop, after Googling, after reading WebMD and Wikipedia and random forum posts on her phone, after going to the public library to access articles in medical journals that existed behind some kind of paywall in the ether, after what would become Yasmin had already begun to germinate, Sosi began to stockpile.*

I wrote Sosi's story in the midst of writing my dissertation. She began to take shape in my mind as I learned more about women's health, read studies about women's health information online, talked to other women about what I was reading, and spent countless hours clicking through Wikipedia articles, their talk pages and revision histories. Would a woman in her thirties track her menstrual cycle? Would she know the timing of menstrual cycle stages—such as ovulation—and know how these stages related to the fertilization, implantation, and maturation of an egg? Would she know that over-the-counter emergency contraception administered orally is not effective at preventing pregnancy if ovulation has already occurred? Where would she go for this kind of information? What if she was unable to access information behind paywalls? How would she make sense of what had happened? What does Wikipedia say about emergency contraception? What does it say about levonorgestrel, the main ingredient in *Plan B,* one of the most popular morning-after pills available in the United States without a prescription? Would Wikipedia be trustworthy? How does Wikipedia's information change over time and how significant are those changes as they relate to a woman using it to inform her understanding of and make choices about her health?

Writing Sosi's story was a way to answer some of my questions about how women seek information about their health. (As Flannery O'Connor observed, "A story is a way to say something that can't be said any other way, and it takes every word in the story to say what the meaning is.") Looking at the revision histories and talk page discussions for the *Emergency contraception* and *Levonorgestrel* articles on Wikipedia and imagining how I might write their stories was another way to answer some of these questions. For example, if Sosi had consulted Wikipedia in 2006, the year the U.S. Food and Drug Administration (FDA) approved nonprescription behind-the-counter access, she would *not* have found an entry for *Plan B*, but she might have discovered the article for *Emergency contraception* was created in 2001 and by 2006 included the following phrase: "[emergency contraceptives] are drugs that act both to prevent ovulation or fertilisation [*sic*] and possibly post-fertilisation [*sic*] implantation of a blastocyst (embryo)." If she had then searched for *levonorgestrel*, she would have learned only that it "is a molecule used in hormonal contraceptives." Five years later in 2011, Sosi would have read:

> Levonorgestrel is used in emergency contraceptive pills (ECPs), both in a combined Yuzpe regimen which includes estrogen, and as a levonorgestrel-only method. The levonorgestrel-only method uses levonorgestrel 1500 µg (as a single dose or as two 750 µg doses 12 hours apart) taken within 3 days of unprotected sex, with one study indicating that beginning as late as 120 hours (5 days) after intercourse could be effective. There are many brand names of levonorgestrel-only ECPs, including: Escapelle, Plan B, Levonelle, NorLevo, Postinor-2, i-pill, "Next Choice" and 72-HOURS.

In 2012, Sosi might have noticed a new section had been added to the *Levonorgestrel* article in response to an editorial in the *New York Times*:

> In June 2012, a New York Times editorial called on the FDA to remove from the label the unsupported suggestion that levonorgestrel emergency contraceptive pills inhibit implantation. A recent review of the scientific literature in the Winter 2013 issue of "The National Catholic Bioethics Quarterly" found that levonorgestrel (LNG-EC) "exerts minimal effects on cervical mucus and sperm function and that suppression of ovulation is not the dominant MOA accounting for the contraceptive efficacy of LNG-EC..." Luteal deficiencies and endometrial changes reported in the literature strongly suggest a postovulatory MOA when LNG-EC is given during the critical preovulatory (or fertile) period.

In other words, Sosi would have learned that suppressing ovulation is not the method of action (MOA) of levonorgestrel at all—but only if she had read the article after 2012. If Sosi had been curious, clicked Talk, and read the *Levonorgestrel* article talk page in 2012, she would have noticed that the editors discussing the article in 2006 were debating whether the article should use the word "persons" or "women" when describing over-the-counter availability and who could purchase the morning-after pill. She may have also noticed that other editors were concerned with the accessibility of the language used in the *Levonorgestrel* article and related articles: "[…] needs some vocabulary explanation for those of us that didn't go to medical school." Finally, Sosi may have noticed that a few Wikipedia editors knew about the MOA of levonorgestrel as early as 2007—five years before the *New York Times* editorial was published.

Would a woman processing an unexpected pregnancy—the result of a one-night stand and the apparent failure of two forms of contraception—dig that deep? According to one interviewee Eileen, yes:

> *I'm an older woman now, and I wrote that [article about miscarriage] for younger women—but that article is unique because one of the ways women cope with that loss is that they seek information. […] It's not a side effect, but like it almost always happens when you have a miscarriage. You don't get enough information at the hospital, or you're told, "Hey, this happens all the time," you know. "One out of four women…" and you're going like, "Whoa, you know, I just lost a ton of blood, and I had all of this pain, and you're telling me that I'm over-reacting, or that you see it all the time, or that, you know, I can get pregnant again?" […] And that's kind of a unique one because all you can do is seek information. You have to find out why, how, is it going to happen again?*

While Eileen spoke to miscarriage rather than unexpected pregnancy, research supports her assertion that women often cope with health events by seeking information. For example, in a study of women with breast cancer, Rees & Bath (2001) found that although information-seeking behaviors were "highly individualistic," many women actively sought information to feel more in control and make informed choices. Overall, research suggests that empowerment of patients results in better outcomes, and information seeking is a primary path to increased health knowledge and subsequent empowerment (Camerini, Schulz & Nakamoto, 2012). As Nasrabadi, Sabzevari & Bonabi (2015) write: "the promotion of women's health information is a fundamental strategy for empowering them."

Although there are many online information sources a woman can turn to for information about her health (e.g., private websites like WebMD; government websites National Institutes of Health's Womenshealth.gov, MedlinePlus, and the Center for Disease Control and Prevention; online communities such as Reddit and Facebook groups), Wikipedia consistently tops search results and ranks as a primary source of health information among patients and providers (e.g., Laurent & Vickers, 2009; Beck, 2014; Heilman & West, 2015). So, it is feasible that Sosi—a woman who exists only in my mind—would want to know why *Plan B* had failed her, would want to know why she was pregnant. And it is feasible she would start with Wikipedia.

Background

> The encyclopaedia was traditionally a mirror of the world (a *speculum*)—of how it was, of how it should be.
>
> Andrew Brown, 2011

> speculum (n.)
>
> 1590s, in surgery and medicine, "instrument for rendering a part accessible to observation," from Latin speculum "reflector, looking-glass, mirror" (also "a copy, an imitation"), from *specere* "to look at, view" (from PIE root *spek- "to observe"). As a type of telescope attachment from 1704.[3]

Wikipedia (wikipedia.org) is the world's largest online encyclopedia and one of the most successful user-generated content (UGC) systems in history. Wikipedia now exists in more than 300 languages and is hosted by the Wikimedia Foundation (WMF), a non-profit organization that "provides the essential infrastructure for free knowledge." People from all over the world edit Wikipedia, with the goal of creating the most extensive repository of information possible. Regular contributors call themselves Wikipedians; they are dedicated to the Wikimedia *movement*—producing and maintaining a collection of sites, events, and projects that value "freedom of speech, knowledge for everyone, and community

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[3] See https://www.etymonline.com/word/speculum

sharing." As Wikipedia co-founder Jimmy Wales noted in 2014, "Some [Wikipedians] are buttoned-down. Some are rock and roll. The articles they write and edit cover everything from aardvarks to ZZ Top. And they're all true believers in Wikipedia's power" ("Wikimania", 2015).

Wikipedia *is* powerful: its content informs multiple information systems (McMahon, Johnson & Hecht, 2017), topping Google search results and shaping the responses of virtual assistants like Siri and Alexa (Withers, 2018). Every day, billions of people visit one of the many Wikipedias where they read articles about natural disasters, politicians, operating systems, television shows, and athletes. Recently, *The Atlantic* described Wikipedia as the "arbiter of truth" in a post-truth world (Madrigal, 2018). In addition to the public recognizing the influence of Wikipedia, technology giants like Amazon and Google as well as human computer interaction (HCI) researchers also have a vested interest in the project (e.g., Vincent, 2018; Matsakis, 2019). For example, Wikipedia is increasingly used to provide content to other systems and to train algorithms and artificial intelligence agents (e.g., Hao, 2018; Bullock & Luengo-Oroz, 2019).

Wikipedia, however, is not without its problems. Wikipedia's guidelines instruct editors not to "bite the newbies," but they also proclaim, "there are no rules," and community norms tend to reward aggressive behaviors such as reverting other people's edits without explanation or comment (Halfaker, Kittur, & Riedl, 2011). As others have noted (e.g., Morgan et al., 2013a; Schneider, Gelley, & Halfaker, 2014; Steinmacher et al., 2015), these cultural contradictions not only make it difficult for newcomers to participate, but also create a labyrinth of spaces that are, at once, safe and unsafe depending upon who the user is and how they navigate passage (Menking, Erickson & Pratt, 2019). Although Wikipedia purports to be the encyclopedia "anyone can edit," as Ford & Wajcman observe, "not everyone does" (2017). By best counts, more than 80% of Wikipedians are men (Hill & Shaw, 2013). This demographic skew in participation has come to be known as the *gender gap* and has received both public (e.g., Cohen, 2011; Paling, 2015; Torres, 2016; Jacobs, 2019) and scholarly attention (see Appendix A).

Though the relationships between Wikipedia's participatory and content gaps have not been empirically established as causal, many researchers have hypothesized a connection between the two. In 2011, Lam and his colleagues were the first to suggest Wikipedia's participatory gender gap has an impact on content: "Coverage of topics with particular interest to females is inferior to topics with particular interest to males" (p. 5). Despite their conflation of sex and gender, operationalization of sex as binary, and stereotypical depictions of what interest men and women (e.g., "[…] males and females are focused on disparate content areas within Wikipedia. There is a greater concentration of females in the People and Arts areas, while males focus more on Geography and Science" (p. 5)), in the conclusion of their paper they suggest other factors (e.g., cultural) and call for more research:

> Taken together, our results […] hint at a culture that may be resistant to female participation. More research, including interviews, surveys, and focus groups, is needed to determine the underlying causes of the problems evidenced by our findings, and to determine what can be done to improve the situation. (p. 9)

Since Lam and his colleagues' study, Wagner and her colleagues (2015) have assessed gender bias across four dimensions (e.g., coverage, lexical, structural, and visibility) and across six language Wikipedias (e.g., English, Russian, Spanish, Italian, French, and German), finding that women are portrayed differently than men in Wikipedia biographies and suggesting the participatory gender gap may be a factor:

> Our results clearly show that subtle lexical and structural gender biases are present on Wikipedia. Potential explanations for these biases are the following: it is possible that biases are a consequence of (i) the predominantly male editor community and the software design in general that might encourage male contributors and/or (ii) historic and present inequalities between men and women that manifest e.g. in unequal access to resources, unequal media presentation and historic documentation and implicit gender stereotyping. (p. 461)

Both of these studies assume a causal connection between who contributes to Wikipedia and what is in Wikipedia, and yet they also recognize this assumption is complicated by other factors, including Wikipedia's culture and existing inequalities and biases outside of Wikipedia.

Relatedly, in addition to the gender gap, Wikipedia evidences other participatory gaps. For example, researchers Mark Graham (Graham, 2011; Graham et al., 2015) and Heather Ford (2011; 2017) have investigated geographical and cultural gaps while social activist groups like AfroCrowd and Black Lunch Table have begun to address racial gaps (e.g., Murphy, 2015; Kessenides & Chafkin, 2016; Frisella, 2017). The non-profit organization Whose Knowledge?, founded by two former Wikimedia Foundation employees, has worked closely with underrepresented groups including the Dalit community, queer and feminist archives in Bosnia and Herzegovina, and Kumayaay Native Americans to facilitate inclusive campaigns and address related content gaps. However, many of these participatory gaps—specifically socio-economic and racial gaps—are currently understudied and undertheorized, particularly in comparison to the gender gap (Shaw & Hargittai, 2018).

Research Problem

From birth to menarche to menstruation to childbirth to menopause, women's bodies shape many of their experiences. Additionally, society's views about and control over their bodies—from expectations about body shape and size (e.g., Kasardo & McHugh, 2015; Lupton, 2018) to sexual objectification (e.g., Zimmerman & Dahlberg, 2008; Szymanski, Carr & Moffitt, 2011) to rape culture (e.g., Buchwald, Fletcher, & Roth, 2005; Harding, 2015) to regulating reproductive health (e.g., Krauss, 1991; Correa & Petchesky, 2007; Flavin, 2008) to limiting where they can go and what they can do (e.g., Valentine, 1989; Day, 1999; Day, 2000)—shape their lives. Yet different women have different experiences of embodiment and face different forms of prejudice and oppression. Race, ability, class, and sexuality—as individual or intersecting identities—all affect the ways in which women move through the world and are treated by others. For example, physicians are less likely to believe and treat pain in Black women (Hoffman et al., 2016), and lesbians experience bias in both physical and mental health care settings (Saulnier, 2002).

Furthermore, because women worldwide shoulder the burden of caring for the young and old, they are also more likely to seek health information and make health-related decisions on behalf of others. Women are, in fact, the "primary consumers" of health information (Norsigian, 1992). Historically, though, women have been barred from participating in the production of health information—even about their own bodies. So, what does one of the world's most powerful information sources—the encyclopedia "anyone can edit"—have to say about their health today? Given what we know about Wikipedia's participatory gaps, who is creating, curating, and controlling women's health information on the English language Wikipedia? Does it matter? What else might matter?

Research questions

The purpose of this inductive, qualitative study is to answer the following research questions:

> *How do Wikipedians who edit women's health content perceive women's health information on the English language Wikipedia? Why do they write it? How do they envision their audiences? What do they think is missing?*
>
> *What can object biographies tell us about the production and neglect of women's health information in sociotechnical systems like the English language Wikipedia? What can they tell us about the reproduction of scientific knowledge related to women's health in public spheres like the English language Wikipedia?*
>
> *In what ways do participatory gaps (e.g., gender, age, race) on the English language Wikipedia shape women's health information on the site?*

In this dissertation work, I use critical inquiry to ask these questions from a feminist perspective. I am particularly interested in *how* women's health information on Wikipedia is produced and *by whom*. I am also interested in how Wikipedia as a sociotechnical system mirrors and perhaps even magnifies existing biases and inequities. Although I do not argue that the relationships between participatory gaps and content gaps are explicitly causal, I do tease out some of the factors that contribute to the production and neglect of women's health information on the English language Wikipedia. I argue that editors' beliefs about gender may be more pertinent than their own gender identities when we are trying to understand how participation impacts content (see Peake, 2015 for a similar argument). Building on prior work (e.g., Ford & Wajcman, 2017; Wagner et al., 2015), I also argue that—beyond the demographics and beliefs of participants—specific aspects of Wikipedia's technical infrastructure, governance, and community norms mirror and perpetuate systemic bias.

Motivation

This study is motivated by a multiplicity of desires: to understand how women's health information on the English language Wikipedia is produced and by whom; to begin to understand the nuanced relationships between participation and content in user-generated content (UGC) systems; and to see an online source like Wikipedia provide free, accurate, and thoughtful information that could help to mitigate existing health disparities. As a feminist researcher, I am also motivated by *social justice feminism*:

> […] social justice feminism reflects dissatisfaction centered more directly on liberal feminism […] [which] has focused primarily on a white, middle class, heterosexual female subject, examining her status when compared with her male counterpart. In its emphasis on formal equality, liberal feminism has failed adequately to address other social and political structures that support patriarchy. Social justice feminism strives to uncover and dismantle those structures, such as white privilege, heterosexism, able-ism, and classism. (Kalsem & Williams, 2010, p. 157)

Wikipedia purports to be the encyclopedia "anyone can edit" and the "sum of all human knowledge," and despite its problems, I still believe in its promise. Founded in 2001, the encyclopedia has now come of age. Like any 18-year-old, it is time to examine habits that ensured survival during childhood and adolescence but that no longer serve a purpose. It is time for Wikipedia to grow up and live up to its promise.

Significance of the Study

Surprisingly, this dissertation work is the first to examine women's health information on the English language Wikipedia explicitly and, thus, makes a clear empirical contribution. Additionally, this dissertation work makes a methodological contribution as I have adapted object biography—a material culture method most often used in anthropology—to study a collection of digital objects. And while this dissertation work focuses only one site of study—the English language Wikipedia—and is limited to only one domain—women's health information—the findings extend beyond the boundaries of Wikipedia by interrogating assumptions about the relationships between participatory and content gaps in UGC systems.

Overview of Dissertation

Below, I provide a brief overview of the chapters in this dissertation.

In Chapter 2, I review relevant literature. Because this dissertation work is situated at the intersections of several scholarly communities and focusses on the topical domain of women's health within the context of the English language Wikipedia, I draw from health informatics, computer supported cooperative work (CSCW), human-computer interaction (HCI), and science and technology studies (STS) as well as medical anthropology and history. I also review studies about general health information and women's health information on Wikipedia. I conclude this chapter with a description of the conceptual framework I developed, drawing from the reviewed literature.

In Chapter 3, I provide a brief overview of Wikipedia. This chapter is intended to provide an introduction to Wikipedia's history, governance, infrastructure, and community for readers who are not familiar with Wikipedia studies. Additionally, I devote two sections to the anatomy of a Wikipedia article and the anatomy of a Wikipedia article page respectively. These sections provide context for the object biographies that follow in Chapters 6 and 7. Finally, I explain why I have chosen the English language Wikipedia as a site of study.

Chapter 4 concerns the methodology of this dissertation work. I discuss my stance as a researcher, including how I used five years of ethnographic research to inform the design of this study, and how I gained access to and became an active member of the Wikimedia communities. I then detail each of the methods I have used: semi-structured interviews, document analysis, and object biography. I describe my data collection procedures and data analysis processes for each method. I then speak to how these methods should be evaluated in the context of this dissertation.

Chapters 5-7 are dedicated to findings from three separate yet interrelated studies.

In Chapter 5, I share findings from interviews with Wikipedia editors who edit women's health content, answering the first set of research questions: *How do Wikipedians who edit women's health content perceive women's health information on the English language Wikipedia? Why do they write it? How do they envision their audiences? What do they think is missing?*

In Chapter 6, I discuss how I used object biography to interrogate three specific Wikipedia articles related to women's health information: *Atrophic vaginitis*, *Vaginal cancer*, and *Women's health*. By telling the life-histories of each of these articles, I answer the first question from the second set of research questions: *What can object biographies tell us about the production and neglect of women's health information on sociotechnical systems like the English language Wikipedia?*

Chapter 7 builds on Chapter 6, answering the question: *What can object biographies tell us about the reproduction of scientific knowledge related to women's health in public spheres like the English language Wikipedia?* In this chapter, I use object biography to interrogate two specific Wikipedia articles that seemed to be outliers in my data: *Abortion-breast cancer hypothesis* and *Coffin birth*.

In Chapter 8, I discuss the findings and implications presented in Chapters 5-7, addressing the final research question: *In what ways do participatory gaps (e.g., gender, age, race, class) on the English language Wikipedia shape women's health information on the site?* Finally, I summarize this dissertation work, outlining its limitations and contributions as well as opportunities for future research.

Chapter 2: Literature Review

Introduction

On the surface, the purpose of this dissertation work is to understand women's health information on the English language Wikipedia. To carry out this study, I needed to read widely and in concert with the research process. Thus, this review was ongoing and iterative—informed by my data collection and analysis. This study reflects the interdisciplinary nature of information science and is in conversation with several constituent communities including CSCW, HCI, and STS.

To conduct my search for relevant literature, I began with the University of Washington's Library online catalog (including articles and research databases), the Association for Computing Machinery (ACM) Digital Library, PubMed, Web of Science, and specific journal websites (i.e., *Journal of Medical Internet Research*, *Journal of the American Medical Association*). I also used Google Scholar and Google Search to identify non-archival, non-peer reviewed sources. Therefore, my literature review consists of books, journal articles, conference proceedings, dissertations, preprints, news articles, newsletters, Wikipedia pages, and blog posts.

The initial keyword search terms I used included: *women's health*, *defining women's health*, *women's health history, women's health information*, *women's health information online*, *women seeking health information*, *health information on Wikipedia*, and *women's health information on Wikipedia*. As I read the sources I gathered, I included additional keywords in my search: *women's health movement, maternal health*, *intersectional health*, and disease and condition specific terms related to my data collection and analysis (i.e., *vaginal cancer, atrophic vaginitis, abortion-breast cancer hypothesis*). I also annotated the references included in the studies I read and searched for related work by frequently cited authors. Over the course of the research process as I shared transcripts with interview participants and kept them apprised of progress, a few interviewees sent me literature they thought would be interesting or relevant; I have included some of their suggestions here. Finally, I searched for literature related to emerging concepts and constructs such as *expertise*, *evidence*, *medicalization*, and *knowledge production*. As this is a qualitative study, in the following chapters I also introduce and discuss literature not included here that is relevant to my findings (Creswell, 2005).

Because I wanted to understand how women's health information on Wikipedia today relates to larger questions of knowledge production (e.g., how knowledge is created and by whom), I did not use any date delimiters for my literature search though in my final selection process I chose to focus primarily on literature published in the last three decades with the exception of seminal works. All of the literature I have included has been published in English and mostly by Western academic institutions or publishers; my discussion of women's health has been limited primarily to the United States.

Below, I present my review of the literature in three topical sections. The first section provides a brief overview of women's health, focusing on definitions, the medicalization of women's health, historical inequities and abuses, and women's responses in the last 60 years. The second section considers women seeking health information both for themselves and on behalf of others and discusses the availability of women's health information online. The final section reviews literature about health information on Wikipedia, concluding with an observation of the dearth of research about women's health information on the English language Wikipedia.[4] Throughout the literature review, I point out important gaps, omissions, assumptions or contested areas and how they relate to my research. I close with an outline of how the literature has contributed to the development of this study's conceptual framework and an interpretative summary of the literature as it related to this dissertation.

Women's Health

> Women are rarely the ones to set the boundaries of the discussions surrounding the identification and definition of their health problems. Women's health, as a discursive field, is usually defined by others.
>
> Marcia C. Inhorn, 2006

On March 23, 2017, the Twitter account for Mike Pence, the Vice President of the United States, tweeted a photo of Pence seated at a large oval conference table surrounded by mostly white men in business suits. The tweet read: "Appreciated joining @POTUS for meeting with the Freedom Caucus again today. This is it. #PassTheBill" (see Figure 1.2). The Freedom Caucus Pence refers to in his tweet consists of the most conservative of House Republicans who vote as a bloc. Although the Freedom Caucus does not disclose the names of its members, by best counts, in March 2017 it included only one woman (Desilver, 2015; Cheney, 2018). The bill Pence refers to in his tweet was the Better Care Reconciliation Act of 2017. Authored by 13 men, the initial bill proposed to repeal the Affordable Care Act, making it more difficult for many women to access health care (Brindis et al., 2017). It was swiftly met with opposition from Democrats and women's and reproductive health advocates. Senator Patty Murray of Washington was the first to respond to Pence's tweet, retweeting the photo and adding, "A rare look inside the GOP's women's health caucus" (PattyMurray, 2017).

It is nearly impossible to consider women's health information on the English language Wikipedia without considering the history of women's health more broadly. As the example above illustrates, decisions about women's health—from defining its scope to determining what constitutes legitimate medical practice to earmarking research funds to drafting policies to enforcing legislature—have often been made (and continue to be made) in the absence of women.

In the following section, I include literature drawn from a wide variety of disciplines, including sociology, public health, medical anthropology, STS, health informatics, and HCI. The topic of women's health far exceeds what I review here. For interested readers, I recommend Loue & Sajatovic (2004); though the statistics cited in the first section of their book are now outdated, the authors present a holistic and accessible overview of women's health in the United States that is still germane today. I also recommend Alexander and colleagues (2017) for a more current introductory text.

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[4] Aside from research about health information on Wikipedia, I do not include literature from Wikipedia studies here. Chapter 3 is about Wikipedia as a site of study and provides a general overview of the site and community as well as a review of work about the participatory gaps, assumptions about related content gaps, and a description of WikiProjects, including WikiProject Women's Health.

Figure 1.2. The image tweeted by Vice President Mike Pence's Twitter account. Retrieved from a BBC article entitled "All-male White House health bill photo sparks anger" (All-male, 2017).

Defining women's health

Defining women's health is one of the most fundamental and critical tasks required for understanding women's health information on the English language Wikipedia. While this may seem like a relatively simple task, it is fraught with epistemological, ontological, political, and practical implications (e.g., Weisman, 1997; Karney, 2007). As Bowker & Star (1999) emphasize in their discussion of the International Statistical Classification of Diseases and Related Health Problems (ICD) classification system as information infrastructure, definitions are not "natural"; they are the result of historically and technologically embedded political interests. Historically, women's health has been defined by men, and the resulting definition has been reductive in the most obvious way: *women reproduce*. Beginning with Greek physicians in 2nd century AD—who believed the "wandering womb" caused a range of illnesses and, in some cases, death (e.g., Micale, 1995; Thompson, 1999)—and continuing into the second half of the 20th century, women have been essentialized as *reproducers*. Thus, policies and care have reflected this mostly top-down, androcentric view of women as "boobs and tubes" (William, personal communication, September 15, 2016)—a view that normalizes a conception of women's health limited to the care, management, and control of female reproductive organs.

But women's health is much more than female reproductive organs. In the past few decades, research has begun to investigate how disease prevention, presentation, and treatment differs between men and women. Because women were historically excluded from medical research both as researchers and as study participants (e.g., Scully, 1980; Dresser, 1992; Heiat, Gross, & Krumholz, 2002; Melloni et al., 2010; Beery & Zucker, 2011; Dusenbery, 2018), we are just now beginning to discover how heart disease affects women, why women are more likely to suffer from migraines and autoimmune disorders, that women are diagnosed years later than men who have the same conditions, and that women may be subject to specific conditions (e.g., Alzheimer's disease, osteoarthritis, rheumatoid arthritis, osteoporosis, and cardiovascular diseases) simply because, on average, they live longer than men. In short, women's bodies are different from men's in a host of ways that impact their health, wellness, and quality of life.

As of July 2019, a cursory review of the ACM Digital Library reveals only 18 results with *women's health* as an author keyword and an additional 49 results (for a total of 67) with *women's health* in any field. Expanding the search to *health* + *gender* as author keywords results in seven items but expanding the search to *health* + *gender* in any field results in 109 items total.[5] While there has been a significant uptick in the number of ACM publications about women's health since 2000 (with a spike in the last two years), the relative lack of HCI research about women's health is disconcerting, and the fact that the majority of these studies focus on maternal and/or reproductive health—thereby reifying a reductive, essentializing definition—is disappointing. For example, the majority of the studies categorized as being explicitly about women's health (the 67 noted above) are dedicated to gynecological or reproductive topics such as menstruation (e.g., Lee et al., 2017; Epstein et al., 2017; Homewood, 2018), pelvic fitness (Almeida et al., 2016), or pregnancy (e.g., Gui et al., 2017; Andalibi & Forte, 2018). Casting a wider net to consider studies about breast cancer, mobile health (mHealth), and healthcare record management, Almeida, Comber & Balaam (2016) also conclude "the vast majority of work within the context of women's health in HCI is focused on maternal care" (p. 2600). This lack of breadth in HCI research points to how the legacy of a restrictive definition of women's health continues to impact a range of diverse fields.

The medicalization of women's health

Peter Conrad (1992), an American medical sociologist, defines *medicalization* as the "process by which nonmedical problems become defined and treated as medical problems, usually in terms of illnesses and disorders" (p. 209). The medicalization of women's health is another arena in which the power to define and categorize has been and continues to be enacted. In particular, reproductive processes like menarche, menstruation, childbirth, and menopause are frequently pathologized and treated as events requiring professional medical intervention (Inhorn, 2006, p. 354). For example, historically, childbirth belonged primarily in the private, domestic sphere—the realm of mothers-to-be, women relatives, and midwives with men occupying the periphery. Children were delivered at home rather than in a hospital, and childbirth was often situated as an important ritual for the woman first, the family second, and then for society at large. In fact, today in many parts of the world, this practice continues (see Inhorn, 2006). However, in the United States, we have seen a rise in what Davis-Floyd (1992) describes as the "technocratic model" of childbirth which prioritizes the knowledge and expertise of obstetricians (not always men) over that of women giving birth. Writing in 1977, Gena Corea observes, "No longer is the American mother an active childbearer [....] Now, strapped down and drugged, she is the object on which the doctor works" (p. 184). While critics may argue that this model guarantees safer births for both mother and child, that is not always the case. Many of the practices (e.g., use of obstetrical instruments like forceps, elective induction, fetal monitoring, episiotomies) that emerged during the medicalization of childbirth in the United States increased risks and caused harm or death (i.e., the Caesarean section was initially fatal for women) (Scully, 1980). While some of these practices have fallen out of favor (i.e., forceps, episiotomies), others like the Caesarean section have been improved

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[5] This is not intended to be an exhaustive search.

upon and are used so frequently that they are now considered consumer-driven options rather than required medical interventions (Malacrida & Boulton, 2014).

How women's health has been and is now defined and medicalized are separate but interrelated topics that merit much more consideration than I have afforded them here. They are also topics inextricably bound up in the history of medicine, a field which (like Wikipedia) has been and—despite significant gains—continues to be dominated and regulated by patriarchal structures (see Garrett, 2018 for a summary of current obstacles for women in medicine and medical research; see Ford & Wajcman for an overview of how patriarchal structures shape Wikipedia's infrastructures). While a more comprehensive discussion of these topics is beyond the scope of this literature review, I have included a brief summary above because Wikipedia is not written in a vacuum but rather is a dynamic, socially constructed and historically and culturally situated object (or collection of objects). Therefore, considering how women's health has been defined and medicalized is necessary background for this dissertation work. In Chapter 5, I discuss how analyzing scope definition discussions amongst members of WikiProject Women's Health and, in Chapter 6, how considering the life-history of the Wikipedia article *Women's health* enables us to identify the ways in which the legacy of a reductive, biomedical conceptualization of women's health shapes online knowledge production—and how some Wikipedians are trying to change this.

A history of bias, discrimination, suppression, and abuses

Given the history of androcentric definitions of women's health, one can imagine the kinds of bias and discriminatory practices that have taken place. From physicians perpetuating notions of female weakness and fragility (Corea, 1977) to reinforcing concepts of hysteria as biologically determined and unique to women (Micale, 1995) to intentionally and systematically discrediting midwives (Jackson & Bailes, 1995) to stigmatizing women's sexuality and pathologizing it as an illness (Corea, 1977) to sterilizing women without their informed consent (e.g., Rodriguez-Trias, 1978; Carpio, 2004; Dorr, 2011), the history of medicine is rife with social control driven by patriarchy, sexism, and misogyny enacted by all genders. As Monica H. Green (2008) writes:

> I propose that it might be worth exploring a gendered history of women's healthcare and fertility control, one based on the premise that knowledge about anatomy, physiology or therapeutics does not arise fundamentally out of one's biological nature but from the experience of living in a social world where all forms of knowledge are gendered, both in their genesis and in their dissemination. As such, medical knowledge, and the practices that arise out of it, proves to be very much a part of history […]. (p. 488)

That is, the ways in which medical knowledge is produced, shared, and confirmed is shaped by institutional and cultural factors that can impact anyone regardless of their gender—that medical knowledge itself is gendered. For example, a physician who is a woman can internalize patriarchal perspectives about gender and then perpetuate sexism in her practice by responding differently to women patients she perceives as promiscuous. The reality, though, is that the field of medicine remains dominated by men. As Suzanne Koven (2017) writes in a letter to young women physicians, women continue to earn less than men, they are less likely to hold leadership positions even in Obstetrics and Gynecology (OB-GYN) where they are a majority, and they are routinely subjected to sexual harassment ranging from "jokes" to physical violence.

From a patient's perspective, Maya Dusenbery's well-researched popular press book *Doing Harm* (2018) frames the systemic biases that continue today as knowledge and trust gaps. Knowledge gaps occur because physicians do not know as much about women's bodies, illnesses, and conditions; whereas trust gaps occur when physicians do not believe women. Though abuses like forced sterilization no longer take place in the United States, doctors still discredit women, questioning the validity of the symptoms they report and doubting their pain (e.g., Ballard, Lowton & Wright, 2006). This latter gap—the trust gap—resonates with what philosopher Miranda Fricker (2007) describes as *testimonial injustice*: "when prejudice causes a hearer to give a deflated level of credibility to a speaker's word" (p. 1). For example, in a recent short film featured in *The Atlantic*, a woman describes how doctors told her to take Ibuprofen and "get on with it" when she sought medical help for her prolonged and painful periods and experiences of extreme pain during sex. This occurred repeatedly over more than 15 years until she was finally diagnosed with endometriosis—a disorder in which tissue that normally grows inside of the uterus grows outside of the it.[6] Similarly, author, model, and actress Padma Lakshmi co-founded the Endometriosis Foundation of America in 2009 after decades of "falling through the cracks" of the medical system and not finding a doctor who believed her until she was 36: "He was the first doctor to make me feel like I wasn't crazy or overdramatic."[7] If a woman like Lakshmi—who is famous and (theoretically) has access to the world's best healthcare—experienced testimonial injustice for more than 20 years, what is the experience like for women who are poor, disabled, or otherwise socially marginalized?

Recognizing this history of bias, discrimination, suppression, and abuses is crucial for understanding how similar power dynamics continue to play out in society and on Wikipedia. For example, in Chapter 5, I discuss how women editors I interviewed relayed stories of "being shouted down" by men on Wikipedia, with three interviewees detailing conflict with the same Wikipedian, who is both a man and a physician. In each of these stories, the women mentioned gender and expertise. (They also discussed their motivations to contribute information about women's health that is based on evidence as well as their lived experiences.) Additionally, I discuss how women interviewees expressed their frustration with the ways in which other editors interpreted Wikipedia's policies about whether the emotional and psychological aspects of health issues constituted "encyclopedic" knowledge and should be included.

Women's responses in the last 60 years

> Indeed, feminism could be described as a movement which, in diverse ways, has been formed against male-dominated expertise. In this sense, activism around expertise has *constituted* feminism.
>
> Maureen McNeil, 1998

The women's health movement (WHM) in the United States radically altered the landscape of women's health beginning in the late 1960s. While the initial focus was on reproductive rights—specifically on legalizing abortion—the movement[8] tackled a range of issues from birth control to the conflation of the clinical and the sexual (i.e., male physicians performing vaginal exams to "prepare" women for marriage; see Lewis, 2005) to the unequal power dynamic between doctor and patient to breast cancer to women in the medical profession. This historical push corresponded with a surge of radical activism and

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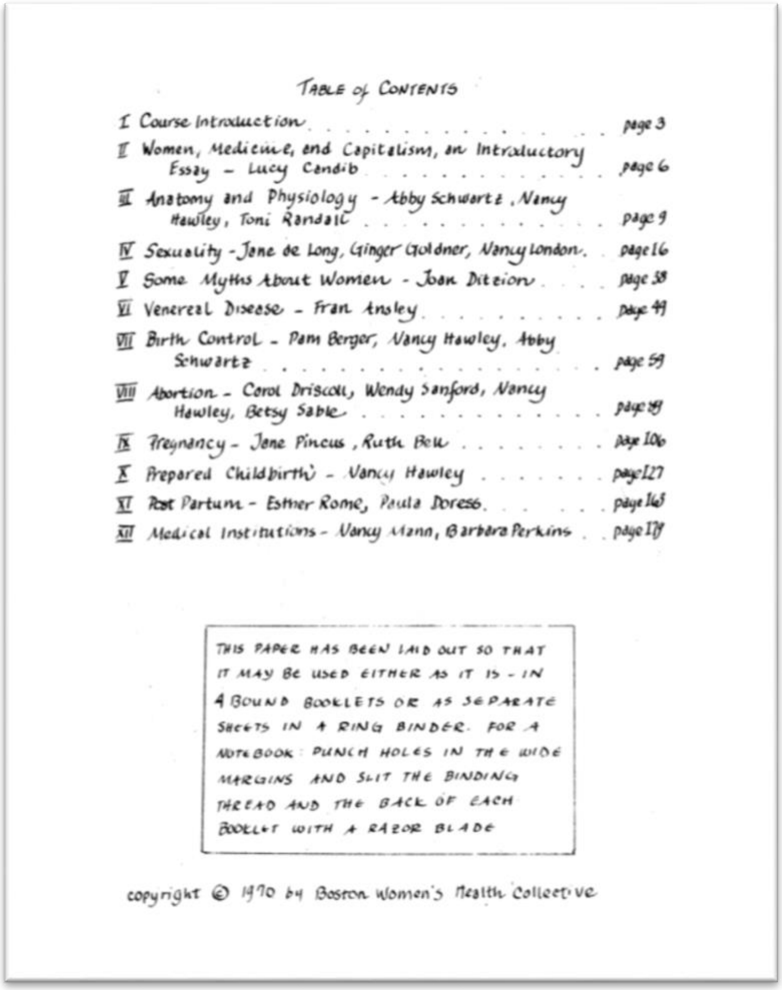
[6] See https://www.theatlantic.com/video/index/582664/endometriosis-sex/

[7] See https://www.endofound.org/padma-lakshmi-s-personal-cause-the-endometriosis-foundation-of-america

[8] For simplicity, I refer to one movement here, but there were, in fact, many splintered initiatives later classified as a *movement*.

resulting social and legal shifts, including second-wave feminism and the broader women's movement in the United States, the civil rights movement, the passing of Title IX into legislation, and the Supreme Court's landmark decision in *Roe v. Wade*.

Maureen McNeil argues that the WHM serves "as probably the most prominent example of the broad-based and diverse feminist activities oriented around the content and practice of expertise" (1998, p. 59). While first-wave feminism challenged women's access to expertise (i.e., women's access to medical schools), second-wave feminism—at its height during the WHM—challenged how expertise was expressed in content (e.g., medical textbooks, leaflets in doctor's offices) and in practice (e.g., resistance to medicalized expertise and male-dominated conceptualizations of women's bodies; see Morgen, 2002). For example, *Our Bodies, Ourselves*, the most recognizable artifact of the WHM, began as a workshop organized and attended by eight middle-class cisgender white women in Boston only to become a touchstone publication that sparked conversations about women's health worldwide. The first booklet produced by the Boston Women's Health Collective, entitled *Women and Their Bodies: A Course,* included co-authored chapters with titles like "Women, Medicine, and Capitalism," "Sexuality," "Some Myths about Women," "Venereal Disease," and "Medical Institutions." See Figure 2.2.



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THIS PAPER HAS BEEN LAID OUT SO THAT IT MAY BE USED EITHER AS IT IS – IN 4 BOUND BOOKLETS OR AS SEPARATE SHEETS IN A RING BINDER. FOR A NOTEBOOK: PUNCH HOLES IN THE WIDE MARGINS AND SLIT THE BINDING THREAD AND THE BACK OF EACH BOOKLET WITH A RAZOR BLADE

copyright © 1970 by Boston Women's Health Collective

Figure 2.2. An image of the hand-written table of contents from the first iteration of what would become Our Bodies, Ourselves.

In the first chapter, "Women, Medicine, and Capitalism: An Introductory Essay," Lucy Candib (Boston Women's Health Collective, 1970) writes:

> We as women are redefining competence: a doctor who behaves in a male chauvinist way is not competent, even if he has medical skills. We have decided that health can no longer be defined by an elite group of white, upper class men. It must be defined by us, the women who need the most health care, in a way that meets the needs of all of our sisters and brothers—poor, black, brown, red, yellow and pink. (p. 6)

In the six decades since the Boston Women's Health Collective published the pamphlet that would become *Our Bodies, Ourselves*, we have witnessed the legalization of abortion (although currently eroding), a broadening definition of women's health beyond reproduction, an increase in women in the medical profession, and an uptick in clinical research devoted specifically to women's health issues. Despite continuing struggles for women's health not to be "defined by an elite group of white, upper class men" (as noted above), the WHM *did* impact women's health policies in the United States. A second wave of women's health activism in the 1990s—led by many of the women who had been involved in or come of age during the WHM—resulted in important changes to mainstream institutions like the establishment of the Congressional Caucasus for Women's Issues, the Women's Health Equity Act, and the 14-year Women's Health Initiative funded in 1993 by the National Institutes of Health (NIH) (Weisman, 1997).

We have also seen a rise, in the past few years, of women-owned health and wellness companies, many of which focus on technologies; this new sector has been dubbed *femtech*, a term coined by Clue co-founder Ida Tin (Collins, 2019). In fact, femtech companies like Clue (a menstrual tracking app), Eve (an at-home testing kit for HPV and other STIs), Thinx (washable, reusable period underwear), and Foria (CBD and THC infused suppositories, supplements, and lubricants) have garnered public attention and an estimated 1.5 billion dollars in venture capital funding since 2014 (Magistretti, 2017). While the rise of the femtech market coincides with the rise of increased technology use in the medical and health field in general, it also signals an unmet need that many women have: to be informed about, to own, and to control their health. For example, menstrual tracking apps were created largely in response to Apple's failure to include menstruation in HealthKit, which they claimed to be the most comprehensive health app of all (Duhaime-Ross, 2014).

From the WHM to femtech, while some women have worked to change existing institutions, others have resorted to working outside of the systems that have failed or excluded them. Earlier this month (July 2019) a new website women's health information site focused primarily on reproductive health and called *Pussypedia* launched in both Spanish and English (Anzilotti, 2019). According to the site's "About" page:

> Pussypedia aims to address the lack of quality, accessible information about our bodies on the internet. Pussypedia is a community-sourced project: the product of people all over the world working together. It is a platform meant to facilitate our ability to collectively generate high quality, accessible information.[9]

What might Pussypedia mean for the future of women's health information on Wikipedia? Is it a signal that working within the system no longer works? I return to these questions in Chapter 8.

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[9] See https://www.pussypedia.net/about

Women Seeking and Sharing Health Information Online

Wikipedia is only one source of women's health information online. As noted in Chapter 1, a woman dealing with an unexpected pregnancy, for example, may turn to private websites like WebMD, government websites National Institutes of Health's Womenshealth.gov, MedlinePlus, and the Center for Disease Control and Prevention (CDC), or online communities such as Reddit and Facebook. Below, I review sources of online health information for women as well as studies about how women use and share this information. I conclude by pointing out the lack of research about how this information is produced and how we might view the rise self-tracking and citizen data initiatives as efforts to fill this gap.[10] Although my study does not focus on women seeking health information or on Wikipedia readers, reviewing this work establishes the pressing need for accurate and accessible women's health information online.

Becoming an informed patient

> our 2nd baby was due yesterday on November 8, but about a month prior to her due date i started getting a strange itching on the palms of my hands and soles of my feet at night. of course i googled it (what else is there to do at 2am when you're wide awake?). and that's when i learned about *Intrahepatic cholestasis of pregnancy*.[11] i told myself, 'don't be ridiculous.' […] i told [my husband] about it, he echoed my feelings. but i had this nagging suspicion that something was not right. i moved my appointment with my OBGYN up to the next day and told her my symptoms. she immediately said i needed to be tested. the following day i was in a mall with a takeaway cup of coffee […] when my doctor called me. my body's bile levels were 'through the roof' and i had to be admitted to the hospital for more tests. i cried in the elevator to the parking lot. we told ourselves, it's fine – at least we caught it in time. what i didn't know was that i'd be scheduled for a c-section a few days later (i never did leave the hospital), and our daughter Eva would be born at 37 weeks. lessons: sometimes googling your symptoms is a good thing! trust your gut. if you feel like something is off then ask your doctor. don't fear being ridiculed.

Diana Moss is a white South African designer and blogger who lives in Cape Town with her husband and two children. I have been following her blog *Miss Moss* for almost a decade. Moss rarely shares details about her personal life, focusing instead on fashion, travel, design, music, photography, and home tours. But after I read the post from which the above excerpt is taken, I was reminded of an article from the *New York Times* my co-advisor had shared with me earlier in the year. In the article, the reporter describes how Serena Williams, an African-American woman and professional tennis player who holds the most *Grand Slam* titles among all active players, was repeatedly denied a computed tomography (CT) scan and blood thinner near the end of her pregnancy despite her insistence that she had a blood clot (Salam, 2018). What do Moss and Williams have in common? Both women listened to their bodies, trusted their own expertise, sought information, and then asked for medical help. While Moss feared "being ridiculed," Williams *was* ridiculed.

The Internet has provided new and unprecedented opportunities for women to become *informed patients*, a possibility many medical professionals have found and continue to find both worrying and threatening (e.g., Hardey, 1999; Cline & Haynes, 2001; McMullan, 2006). For example, some medical professionals have expressed concern about the quality of health information available online (e.g., Hardey, 1999; Eysenbach, Powell, Kuss & Sa, 2002) while others have expressed concern about the

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[10] I limit my discussion to information-seeking via websites and information-sharing via social platforms and apps. I do not discuss telemedicine or patient portals, but I do touch briefly on self-tracking and citizen data initiatives. For a typology of digital health technologies, see Lupton (2014a).

[11] In this her blog post, Moss link *Intrahepatic cholestasis of pregnancy* to the English language Wikipedia article of the same name.

deprofessionalization of medicine as the Internet grants laypeople access to medical expertise (Broom, 2005). At the heart of the conceptualization of the *informed patient* are questions about expertise, agency, and—as Kivits (2004) notes—reflexivity. Kivits (2006) writes:

> The "informed patient" notion refers to people's capacity for searching for more information in order to complete medical information delivered by health and medical professionals, in that way constituting a specific knowledge that can be invoked against doctors' medical knowledge. (p. 278)

Along with the women's health movement in the United States, which was largely responsible for questioning medical expertise in general, the notion of the "informed consumer" has also emerged in the last few decades in healthcare (e.g., Kenkel, 1990; Fox, Ward & O'Rourke, 2005; McMullan, 2006), pushing back on previously established power dynamics between patients and providers. As noted in the opening example, Diana Moss was able to use Google and Wikipedia to learn more about the symptoms she was experiencing during pregnancy and ask for help and, yet, she still doubted herself (her husband reinforced that doubt) and felt fearful. Writing 15 years ago, Hart and her colleagues (2004) noted that all of their interviewees—47 patients and 10 healthcare practitioners—talked about the "symbolic power of the Internet." Today, with the proliferation of digital information sources and misinformation, the Internet's power to create *informed patients* has become both literal and contestable.

Online sources of women's health information

Informational websites

Today, there are numerous online information sources about women's health, including informational websites entirely devoted to or featuring pages dedicated to women's health content (see Table 1.2). Several of these sources continue to reflect what Inhorn (2006) describes as "biomedical hegemony," fracturing women's bodies into disconnected parts to be treated without attention to the worlds in which they live, or the sociopolitical forces (e.g., patriarchy, poverty, racism) that govern those worlds and, consequently, women's bodies. For example, Medline Plus, a medical library, organizes the majority of its content according to biomedical definitions of women's health (e.g., "AIDS in Women," "Breast Diseases," "Cervical Cancer," "Childbirth"), but also includes articles like "Domestic Violence" and "Baby Blues." Similarly, the National Institutes of Health (NIH) Office of Research on Women's Health website organizes information around the "basic, translational, and clinical research on the role of sex and gender in health and disease and sets NIH research priorities in diseases, disorders, and conditions that primarily affect women." There are exceptions to this rule: for example, the website for the World Health Organization addresses the "sociocultural factors" that impact women's health globally.

The majority of the informational websites dedicated to women's health content are either government-run sites—overwhelming supported by the U.S. Department of Health and Human Services—or for-profit ventures supported by ad-based revenue (see Table 1.2). Among the latter group, a review of privacy policies reveals that sites like Healthline, Mayo Clinic, and WebMD, not only collects user information to target advertisements but also to rent or sell user information to third-party companies. Wikipedia and the relatively new Pussypedia are important exceptions in this information ecosystem because they rely primarily on user-generated content and donations.

Table 1.2. A list of informational websites dedicated to or including women's health content. Aside from Wikipedia, Pussypedia, and the WHO, sites are either supported by the government—overwhelmingly the U.S. Department of Health and Human Services—or by for-profit, ad-based revenue models. The text in the About column was taken from each site with emphasis added to draw attention to how authors of the site situate it as an information source.

Site	About	Model
Centers for Disease Control & Prevention (CDC) Office of Women's Health www.cdc.gov/women/index.htm	"The CDC Office of Women's Health (OWH) promotes **public health research**, evidence-based programs, policies, and strategies to improve the health and safety of all women and girls."	*Government*
Healthline www.healthline.com	"We **want to be your most trusted ally** in your pursuit of health and well-being."	*Ad-based revenue*
Mayo Clinic www.mayoclinic.org	"The **product development team** consists of experts in content development and production, product management, and user experience and design."	*Ad-based revenue*
MedlinePlus Women's Health medlineplus.gov/womenshealth.html	"MedlinePlus is the National Institutes of Health's Web site for patients and their families and friends. Produced by the National Library of Medicine, the **world's largest medical library**, it brings you information about diseases, conditions, and wellness issues in language you can understand."	*Government*
National Institutes of Health (NIH) Office of Research on Women's Health orwh.od.nih.gov	"ORWH was established in September 1990 in response to congressional, scientific, and advocacy concerns that a lack of systemic and consistent inclusion of women in NIH-supported **clinical research** could result in clinical decisions being made about health care for women based solely on findings from studies of men—without any evidence that they were applicable to women. ORWH […] works in partnership with the 27 NIH Institutes and Centers to ensure that women's health research is part of the scientific framework at the NIH […]."	*Government*
Office on Women's Health www.womenshealth.gov	"The HRSA Office of Women's Health (OWH) leads women's health-related activities across the agency. We support programs that provide health care to women and girls who are **geographically isolated, economically or medically vulnerable**."	*Government*
Pussypedia www.pussypedia.net	"Pussypedia is a **free, bilingual encyclopedia** of the pussy* made for you to understand."	*Originally crowd-funded via Kickstarter with content written and fact-checked by unpaid contributors; now accepting donations and selling swag*
WebMD Women's Health www.webmd.com/women/default.htm	"The WebMD **content staff** blends award-winning expertise in medicine, journalism, health communication and **content creation** to bring you the best health information possible."	*Ad-based revenue*
Wikipedia www.wikipedia.org	"Wikipedia is a multilingual, web-based, **free-content encyclopedia project** supported by the Wikimedia Foundation and based on a model of openly editable content."	*Supported by a non-profit, charitable foundation, user generated content, and unpaid labor*
World Health Organization (WHO) Women's Health www.who.int/topics/womens_health/en/	"Being a man or a woman has a significant impact on health, as a result of both biological and gender-related differences. The health of women and girls is of particular concern because, in many societies, they are disadvantaged by **discrimination rooted in sociocultural factors**."	*Supported by United Nations agency funded via member states and contributions*

Women sharing health information

Women as health brokers

Although the focus of this study is on the creation, curation, reproduction, and neglect of women's health information and *not* on information-seeking and consumption, it is important to note that the women who come to Wikipedia may be seeking information not only on their own behalf but also on the behalf of other women in their lives—daughters, mothers, grandmothers, aunts, nieces, friends. Women often serve as "health brokers" (Norsigian, 1992), meaning they are generally more engaged than men are in seeking health information. Consequently, women are the primary consumers or "major users" (Norsigian, 1992) of health information and, therefore, frequently evidence higher levels of health literacy than men do (Paige, Krieger & Stellefson, 2017). Additionally, as researchers have observed, women represent the majority of health care workers, so they are not only consuming and sharing health information informally, they are also disseminating it in professionalized healthcare settings (e.g., Fontenot, 2012; "Women make up most," 2017). We also know women share health information across a variety of platforms, including blogs, subreddits, Facebook groups, and Twitter (e.g., De Choudhury, Morris & White, 2014; Harpel, 2018; Alquassim et al., 2019). Some of these platforms are designed explicitly for information-sharing (i.e., the affordances of private Facebook groups) and some have been adapted by users so that they might create spaces to connect (i.e., the use of hashtags and direct messages on Instagram; see Nazanin Andalibi's work about women's disclosures of depression, eating disorders, self-harming, and miscarriages). Researchers have found that, in addition to women serving as "health brokers" online, women also seek and share psychological, emotional, and social support when dealing with health conditions (e.g., Evans, Donelle & Hume-Loveland, 2012; Peyton et al., 2014; Young & Miller, 2019). For example, in their study of how women with vulvodynia engage via a private Facebook group, Young and Miller (2019) discuss how women with this painful, chronic, and enigmatic condition "co-construct an understanding of their condition, build personalized management plans, and devise ways to be taken seriously by providers" (p. 9).

Sharing via specialized apps and platforms

Recently, several specialized apps and related online communities have sprung up to meet the needs of women looking to share health information with one another in a safe, supportive environment. Take, for example, Peanut—a mobile app designed for women who are mothers that "facilitates conversations that women want and need to have."[12] Or, as the *New York Times* describes Peanut, an "app for mothers who missed out on Tinder" (Kercher, 2017), designed (not surprisingly) by a woman who was also involved in creating two popular dating apps. Other examples include The Bump, which features active message boards about pregnancy, RealSelf, an app and community "built […] as the destination for people to learn about cosmetic procedures, share their experiences, and connect with top providers" used primarily by women, and Lisa Health, a "start-up that is working to support women approaching menopause with accurate information" (Das, 2019).[13,14] The rise in these kinds of specialized apps and platforms coincides with the rise of femtech, signaling a growing demand amongst women to be able to seek and share health information in safe spaces that center women's voices and embodied expertise.

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[12] See https://www.peanut-app.io/about-us

[13] See https://atwork.realself.com

[14] I briefly worked part-time for RealSelf more than a decade ago.

The rise of self-tracking and citizen science

We can also understand the relatively recent rise in self-tracking as a signal that women, at the very least, want to be informed health consumers. As noted above, Apple's failure to account for menstruation in their Health app prompted a surge of menstrual tracking apps vying to meet consumer needs. Startups, like Clue, Kindara, and Glow, have garnered millions of dollars in venture capital because they promise precise data analytics in service of informing users about their periods (Magee, 2015; Lomas, 2015). With the slogan "your fertility in your hands," Kindara also markets a connected thermometer that collects basal body temperature and then ports the data into the app for analysis (Magee, 2015). As Glow Executive Chairman and former CTO of PayPal Max Levchin claimed, infertility is an information problem that can be solved by applying data (Williams, 2013). Relatedly, self-tracking apps for non-reproductive conditions like diabetes, cardiovascular health, and obesity also make similar promises about the power of datafication (Ruckenstein & Schüll, 2017). Although some women have embraced self-tracking across a range of health conditions, others have rejected it, criticizing the notion of the "quantified self" as an extension of patriarchal surveillance, biomedicalization, and the normalization of women's bodies (e.g., Lupton, 2014b; Sanders, 2016).

Citizen science initiatives, on the other hand, make different claims about the power of user-generated health data. For example, Citizen Endo, a research project at Columbia University led by the Department of Biomedical Informatics asks women with endometriosis to contribute data about their experiences with the disease, which impacts one in 10 women and yet, as noted above, is under researched and often goes undiagnosed (McKillop et al., 2016; McKillop et al., 2018). The differences between initiatives like Citizen Endo and menstrual tracking apps like Glow and Kindara are important to note here. While the latter are for-profit ventures that offer little transparency about how intimate data is stored and used, the former seek to address a lack of understanding about specific diseases and health conditions by engaging women as active participants in medical research. Taken together, the proliferation of self-tracking apps—particularly for women's reproductive health—and citizen science initiatives aimed at understanding under researched conditions like endometriosis underscore women's frustration with currently available health information and express their desire to have more agency and control (even if, in some cases, it is illusionary) in matters of health.

In summary, we know women seek and share health information online. In fact, women are more likely than men to do so because they often serve as "health brokers" for other people in their lives and evidence greater health literacy than men. However, despite research about how women seek and share health information online, an increase in apps and online spaces devoted explicitly to women's health, and the recent rise in self-tracking and citizen science data initiatives, there is still little research about how online information about women's health is produced and by whom (Young and Miller's recent paper, however, touches on co-constructing understanding and sense-making). This dissertation work seeks to address this lacuna by interrogating women's health information on the English language Wikipedia to understand who is creating, curating, and controlling women's health information on the site. Given the ways in which data from Wikipedia has become integrated into other information systems (e.g., informing Google search results, training algorithms, populating virtual assistants' responses), it is crucial to health literacy today to question the accuracy, reliability, and potential biases of women's health content on Wikipedia.

Health Information on Wikipedia

In the following sections, I provide an overview of research about general health information on Wikipedia and then comment on the absence of research explicitly about women's health information on Wikipedia. I also briefly discuss WikiProjects, including WikiProject Medicine. For more information about WikiProjects in general and WikiProject Medicine and WikiProject Women's Health specifically, please see Chapters 3 and 5.

General health information on Wikipedia

A WikiProject (WP) is a group of Wikipedians who work together either to accomplish specific editing tasks (i.e., copyediting, assessing the quality of articles) or to create, edit, and maintain content related to a particular topic (e.g., mathematics, video games, women scientists). The English language Wikipedia currently has over 2,000 such projects. WikiProject Medicine is one example: a relatively small, yet highly productive WikiProject, responsible for the creation, maintenance, or curation of more than 40,000 articles over the past 15 years.

WikiProject Medicine's efforts in combination with search engine algorithms have helped to make Wikipedia a "prominent source of online health information" (Laurent & Vickers, 2009). Consequently, general medical and health information on Wikipedia has received a significant amount of attention from researchers (e.g., Leithner et al., 2010; Kupferberg & Protus, 2011; Fahy et al., 2014; Patel et al., 2015), with many of these studies having been conducted by medical professionals who are also involved in the editor community. For example, James Heilman—a long-time editor and an advocate for the improvement of health-related content on Wikipedia who is also a site administrator and Wikimedia Foundation board member—has co-authored more than a dozen publications about medical and health information on Wikipedia (e.g., Apollonio et al., 2018; Tackett et al., 2018; Azzam et al., 2017; Scaffidi et al., 2017; Masukume et al., 2016; Heilman, 2015; Heilman & West, 2015). One of these publications (Shafee et al., 2017) proposes that the medical community should prioritize contributing to Wikipedia because it is "a key public health information source." Indeed, despite researcher and practitioner misgivings about the site (e.g., Clauson et al., 2008; Buhi et al., 2009; Metcalfe & Powell, 2011; Reavley et al., 2011; Bould et al., 2014), studies in the last five years suggest that Google and Wikipedia independently and together are "important emerging sources of patient health information" (Fahy et al., 2014). In fact, McIver and Brownstein (2014) found that "Wikipedia usage accurately estimated the week of peak influenza-like illness (ILI) activity 17% more often than Google Flu Trends data and was often more accurate in its measure of ILI intensity." And it is not only patients who depend on Wikipedia; a large percentage of medical students (90% according to one study) and physicians (70% according to another study) also consult the online encyclopedia (Allahwala, Nadkarni & Sebaratnam, 2013; Hughes et al., 2009; Beck, 2014).

Public perceptions of general medical and health related content on Wikipedia as reported by popular media sources have also begun to increasingly favor the site. Just this year, *Slate* published an article entitled "Why Wikipedia's Medical Content is Superior," citing a *JMIR* study (Scaffidi et al., 2017; co-authored by Wikipedians, as noted above) that found Wikipedia out-ranks other medical sources (e.g., UpToDate and digital textbooks) when it comes to "short-term knowledge acquisition" (Harrison, 2019a).

Women's health information on Wikipedia

> Before Wikipedia points a finger that might rightly be pointed back at us, let me acknowledge that Wikipedia's shortcomings are absolutely real. Our contributors are majority Western and mostly male, and these gatekeepers apply their own judgment and prejudices. As a result, Wikipedia has dozens of articles about battleships and not nearly enough on poetry. We've got comprehensive coverage on college football but significantly less on African marathoners. At the same time, Wikipedia is by design a living, breathing thing—a collection of knowledge that many sources, in aggregate, say is worth knowing. It is therefore a reflection of the world's biases more than it is a cause of them.
>
> Katherine Maher, 2018

The excerpt above is from a blog post written by Katherine Maher, the Executive Director of the Wikimedia Foundation (WMF), in response to the media's criticism of Wikipedia after reporters discovered the article for Canadian physicist Donna Strickland, a Nobel Prize winner, had previously been deleted due to notability concerns (Koren, 2018). While Maher's point is valid in many cases, there are, in fact, millions of public freely available, peer-reviewed sources that indicate information about women's health is knowledge "worth knowing." Yet, despite significant research about medical and health information on Wikipedia, there is a dearth of research that is explicitly about women's health information on Wikipedia. Important exceptions include studies focused on specific conditions and diseases, particularly those that effect female reproductive organs. One such exception (Lopez et al., 2016) considers health information about cervical cancer, HPV, and vaccines on the Spanish language Wikipedia, finding the content "was accurate" with the exception of a few omissions.

Despite this dearth of research about women's health information on Wikipedia, a range of community groups, professional organizations, and non-profits have begun to improve content with a noticeable uptick in activity since 2014. At times these initiatives have been indirect, such as edit-a-thons hosted by the National Network of Libraries of Medicine (NNLM) or the Cochrane-Wikipedia partnership which is concerned with medical information in general, or more targeted, such as the "Make the Breast Pump not Suck Hackathon" organized by the Massachusetts Institute of Technology (MIT) Media Lab in 2018. Overall, these endeavors—often originating from outside of the Wikipedia communities—signal an interest in improving women's health information on the site.

To date and to the best of my knowledge, women's health information on the English language Wikipedia has not been explicitly and intentionally studied. Moreover, studies (e.g., Farič & Potts, 2014; Holtz et al., 2018) of Wikipedians who edit health information have disproportionately included men (for example, in Farič & Potts' 2014 study about editors' motivations, only one of 32 interviewees was a woman), and publications about general health information on Wikipedia have been authored primarily by men.

Conceptual Framework

Based on the literature reviewed above, I have developed a conceptual framework for this study that draws heavily from feminist HCI and feminist STS. The following concepts are central to my findings in Chapters 5-7 as well as my discussion in Chapter 8 and are expanded upon in more detail there. Below, I provide a brief overview and operationalization of each key concept organized alphabetically.

Expertise

Over the past two decades, HCI and CSCW researchers have considered expertise in variety of settings and systems (e.g., Powell, Klein & Connell, 1993; McDonald & Ackerman, 1998; Vera et al., 1998; Zhang et al., 2007; Civan et al., 2009; Yarosh, Matthews & Zhou, 2012), and although much has been written about expertise in HCI, the definition of "expertise" is often inconsistent. Some of the earliest work (Chase & Simon, 1973) about expertise—or *outstanding* individuals—"argued that the main differences among masters, experts, and novices in a wide range of domains were related to their immediate access to relevant knowledge" (Ericsson & Smith, 1991, p. 26); thus, they positioned expertise as acquired (rather than inherited, for example) and improved on by practice. Similarly, Dörner & Schölkopf (1991), citing Prussian military theorist Carl von Clauseiwtz, argue that expertise is best illustrated when a person "pays close attention to the specific configuration of the facts at a given time" and then draws on relevant knowledge to adapt accordingly (p. 237).

Both of these early conceptualizations of expertise do not conflate it with professionalization (a later development), an important point when considering a domain like women's health in which patient expertise is frequently disregarded by medical professionals (e.g., Boneham & Sixsmith, 2006; Ehrenreich & English, 2013) and/or becomes a site of additional, uncompensated labor (e.g., Lowe, 2005; Seear, 2009). Thus, for this dissertation work, I do not conflate expertise with professionalization, but I do pay attention to how others (including the Wikipedia community as expressed in their social norms) define expertise and question whether they are making this rhetorical claim (conflating professionalization with expertise) perhaps without knowing it. I also draw heavily from Maureen McNeil's (1998) historical account of gender, expertise, and feminism to interrogate issues of gender, expertise, and authority. As McNeil writes, "Work pursuing gender relations has exposed the social and political construction of expertise" (p. 57). This lens is particularly relevant in Chapters 5-7.

Feminist epistemologies

As feminist epistemologist Lorraine Code writes, "Questions about knowledge are implicated in all aspects of women's oppression" (1991, p. 176). Like feminist theory, feminist epistemology is comprised of a set of positions that vary along a number of dimensions, each of which may be described as more or less "radical" depending on how one understands them to diverge from "traditional" accounts of things like the knowing agent and knowledge production. However, there are two specific aspects of feminist epistemologies that are relevant for this dissertation work. First, *knowledge is situated*—knowledge is not something held by abstract, featureless epistemic agents, but rather by real people with particular contingent histories and backgrounds that constrain and delimit what they can and do know. Second, rather than focusing my analyses on knowledge as the product of unspecified, black-boxed machinery, I am interested in the epistemic processes resulting in knowledge. Instead of analyzing what knowledge is, I aim for an account of *how knowledge is produced and reproduced*.

In this way, I draw from early feminist epistemology work (Harding & Hintikka, 1983) that deconstructed perspectives and assumptions, including scientific theories, historically considered to be "neutral" or "objective" to demonstrate the role of patriarchal ideologies and oppressions. I also draw from work that underscores the importance of a knower's position in a society structured by categories like gender, race, and/or class (e.g., Hartsock, 1983; Collins, 1990; Wylie, 2003; Harding, 2009) and, while this approach—*standpoint theory*—has been criticized as being essentialist and as creating insurmountable barriers between knowers, it is useful for understanding how the underrepresentation of women (e.g., the participatory gender gap on Wikipedia) can potentially create a dominant perspective that shapes the kinds of knowledge produced in a given community.

Knowledge production

I have chosen the phrase *knowledge production* to highlight the social construction of knowledge that takes place in online environments like Wikipedia where the inclusion of information is constantly negotiated. As Hara and Sanfilippo (2016) observe, in the case of scientific knowledge, facts and findings are debated even amongst scientists, which then requires laypeople to interpret contradictory understandings of a given phenomenon. This concept is key to my findings and discussion in Chapters 5-8.

Medicalization

As Inhorn (2006) writes, *medicalization* is "the biomedical tendency to pathologize otherwise normal bodily processes and states" (p. 354). In my interviews with editors of women's health information on Wikipedia, the women editors who were not trained as medical professionals described what they call a recent move (within the last five years) to medicalize women's health information on the site.

Patriarchy

By definition, *patriarchy* means a "system of society or government by fathers or elder males of the community." More broadly, patriarchy describes a system of oppression based on male dominance and subsequent sexism. I borrow from Walby's (1989) theorizing of patriarchy in which she identifies six main structures that contribute to a patriarchal system: "a patriarchal mode of production in which women's labour is expropriated by their husbands; patriarchal relations within waged labour; the patriarchal state; male violence; patriarchal relations in sexuality; and patriarchal culture" (p. 220). Most relevant to this dissertation work is the patriarchal state, patriarchal relations in sexuality, and patriarchal culture. It is also important to note here that patriarchy is a *social structure* that is not determined by biology and under which there are individual differences.

Summary

In summary:

- Women's health has often been defined by men—largely in the absence of women—in a way that frequently reduces women to reproducers.
- The medicalization of women's health has resulted in a perspective that pathologizes normal reproductive processes.
- The history of women's health is one marked by systemic biases, disparities, suppressions, and abuses. Women who have less power are more frequently and severely impacted by these inequities.
- Women often take on the burden of seeking health information not only for themselves but also for others. They are also more invested in performing as informed patients.
- The majority of research about women's health information online has focused either on information seeking or sharing rather than on how information is produced and by whom.

- While researchers have considered medical and health related information on Wikipedia in general, women's health information on Wikipedia has received very little scholarly attention.

In addition to these summarizing points and the key concepts listed above, I want to draw the reader's attention to the compounding biases inherent in each layer of this dissertation work. Peeling back these layers and articulating how they impact women's health information on the English language Wikipedia is a challenging task. I cannot, within the scope of this work, account for every variable. I am most interested in teasing apart (1) how the design (e.g., infrastructure, policies, practices, norms) of a UGC system like Wikipedia might reinforce or magnify existing biases and inequities and (2) the ways in which we can think about the connections between participatory gaps and content gaps without assuming that a lack of participations from any one demographic group (e.g., women, African-Americans, editors over the age of 65) is the *sole* cause.

Chapter 3: Wikipedia as a Site of Study

Introduction

Wikipedia is like Wi-Fi. Every day, millions of people use it, depend on it, and expect it to be there. But most of us do not understand how it works, where it comes from, or the costs—both fiscal and human—of making it freely available. Below, I provide a brief overview of Wikipedia, including a discussion of Wikipedia's origins, governance, infrastructure, and community, and a description of WikiProjects, specifically WikiProject Women's Health, as well as the anatomy of Wikipedia articles and article pages. My goal is threefold: (1) to provide an introduction to Wikipedia for readers who may not be familiar with the intricacies and nuances of the site and its communities; (2) to situate this study within the Wikipedia literature, specifically research from HCI, CSCW, and STS; and (3) to explain why I have chosen the English language Wikipedia as a site of study. This chapter is not intended to be an exhaustive introduction to Wikipedia. For readers who are interested in learning more about Wikipedia, I recommend Ayers, Matthews & Yates (2008) and Jemielniak (2014). For a critical overview of Wikipedia, I recommend Lovink et al. (2011).

Wikipedia

> I am afraid I am getting an undeserved reputation as someone who is opposed to everything Wikipedia stands for. This is completely incorrect. In fact, I am one of Wikipedia's strongest supporters. I am partly responsible for bringing it into the world […] and I still love it and want only the best for it. But if a better job can be done, a better job should be done. Wikipedia has shown fantastic potential, and it is open content—and so if the project has problems (or features) which will keep it from being the maximally authoritative, broad, and deep reference that I believe could exist, I firmly believe that the world has the right to, and should, improve upon it.
>
> Larry Sanger, 2005

Today Wikipedia[15] exists in more than 300 languages. Relying on a vast and often invisible infrastructure made up of software, servers, paid employees, and unpaid volunteers, Wikipedia has become one of the most ubiquitous and influential online information sources. According to Alexa rankings, the English language Wikipedia consistently weighs in as one of the top ten most popular websites in the world.[16] Furthermore, Wikipedia's content is seamlessly incorporated into other information ecosystems from Google search results (Vincent et al., 2019) to virtual assistant responses (McMahon, Johnson & Hecht, 2017; Withers, 2018) to BuzzFeed articles (Bassi, 2018) to self-published books sold for profit on Amazon (Josh, personal communication, November 7, 2017). Increasingly Wikipedia's collaboratively authored, edited, and maintained content is also used to train algorithms and artificial intelligence programs (Vincent, 2018).

Wikipedia is one of the most successful cases of *commons-based peer production systems*—systems in which large numbers of people work collaboratively and voluntarily sometimes without financial

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[15] When people say "Wikipedia," they often mean different things. In this study, *Wikipedia* is used to refer to both the website—the free, online encyclopedia—and the editing community: *the phenomenon of Wikipedia*. It is not used to refer to the Wikimedia movement or to 'sister projects' such as Wikimedia Commons, Wikinews, or Wikidata.

[16] See https://www.alexa.com/siteinfo/wikipedia.org

compensation—in history.[17] This fact alone has led researchers to study the site and its constituent communities simply to understand better what motivates people to contribute (e.g., Kuznetsov, 2006; Rafaeli & Ariel, 2008; Lampe et al., 2010; Antin, 2011; Chakraborty & Hussain, 2018). Moreover, because the vast majority of Wikipedia's data—including article contents, talk page conversations, and revision histories—are free and publicly accessible, Wikipedia, the website, has become a favorite object of study for many researchers (see Mesgari et al., 2014).

The English Language Wikipedia

The English language Wikipedia (hereafter referred to as EN Wikipedia) is the oldest and largest Wikipedia. As of January 2019, EN Wikipedia consists of more than 5.7 million articles. Founded on January 15, 2001 by Jimmy Wales and Larry Sanger, EN Wikipedia began as a content production project for their expert-written online encyclopedia, Nupedia. Wales and Sanger did not intend for Wikipedia—a content feeder project for Nupedia—to supplant Nupedia or to be free (English Wikipedia, n.d.). But Nupedia, which depended upon experts and a peer review process similar to academic peer review, languished, and Wikipedia quickly superseded Nupedia. Two years after Wikipedia's start, Nupedia was abandoned and Wikipedia cannibalized its contents.

Because EN Wikipedia is the oldest and largest Wikipedia, certain aspects of its identity, governance, and community are unique. For example, EN Wikipedia is often the first to introduce certain conventions, policies, and features; it also evidences one of the larger gender gaps in participation (Hill & Shaw, 2013; Massa & Zelenkauskaite, 2014). Also, unlike some other Wikipedias, the articles on EN Wikipedia are more likely to be translated into other languages.[18] Finally, EN Wikipedia has its own administrators, bureaucrats, and Arbitration Committee; thus, its governance is localized to some degree.

The Wikimedia Foundation

Two years after Wikipedia was founded, Jimmy Wales established the Wikimedia Foundation (hereafter referred to as the WMF or the Foundation) to fund Wikipedia and related projects. Today the WMF is a 501(c)(3) tax-exempt non-profit organization with physical offices in San Francisco. It owns, operates, and controls the servers and software that enable Wikipedia and related projects like Wikimedia Commons to stay up and running. The WMF also owns, operates, and controls the budget to support community-based programs and initiatives. To do this, the Foundation employs more than 280 people: product engineers, user-experience (UX) designers, software engineers, data analysts, researchers, program officers, community advocates, legal counsel, and organizational support staff. In the last few years, the WMF has taken a more public role that extends beyond the interests of Wikipedia, speaking out on a range of topics from the Stop Online Piracy Act (SOPA) to opposing proposed copyright reform in the European Union to filing a lawsuit against the United States' National Security Agency (NSA).

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[17] Yochai Benkler (2003) coined the term *commons-based peer production* (CBPP) to describe a specific socioeconomic system of production made possible by digitally networked environments, specifically the Internet. Other examples of commons-based peer production systems include Linux, Slashdot, and OpenStreetMap.

[18] See https://en.wikipedia.org/wiki/Wikipedia:Translate_us.

Governance

Though the WMF owns, operates, and controls the servers and software that enable Wikipedia, it does not govern the site (see Figure 1.3). In fact, for legal reasons, the Foundation is mostly uninvolved in the day to day governance of Wikipedia, including the creation and implementation of policies. Occasionally the WMF intervenes when there are extreme cases that put the Foundation at risk (i.e., child pornography). Wales retains some *ad hoc* authority, including holding the founder's seat on the WMF Board of Trustees; however, he is unable to undermine community consensus and decisions made by the Arbitration Committee, a group of elected Wikipedians who resolve cases raised by the community.

The relationship between the WMF and the community of editors is a complicated one that occasionally sparks with tension and discord. For example, when the WMF decided the Visual Editor—a rich text editor that enables people to edit without having to learn wiki markup—would be the default option for all editors, the community demanded that wiki markup remain the default option.[19] Likewise, when the Foundation rolled out "superprotect"—a feature that allowed only WMF employees to make changes to articles under this level of protection, and it was used to override community consensus on the German language Wikipedia the day it was implemented—the community revolted, blocking WMF Deputy Director Erik Möller from the German language encyclopedia for one month.[20] As a direct result of community dissent, the Visual Editor remains optional and the WMF removed "superprotect" from all language Wikipedias after a year.[21] More recently (June 2019), in an unprecedented move, the WMF banned an administrator for one year for reportedly harassing at least 11 other editors over the past several years. This act has since resulted in the resignation of dozens of editors and administrators and may signal a change in the relationship between the WMF and the community of editors, particularly when it comes to how the site handles harassment (Harrison, 2019b).

Wikipedia—the website—declares, "We're all volunteers here. There are no bosses or paid supervisors" (A primer, n.d.). While it is true there are no bosses or paid supervisors, Wikipedia's system of governance is at once highly defined, well-documented, and a snarl of paradoxes. Researchers have described it as similar to traditional organizational groups, as an exemplar of peer governance (Forte, Larco & Bruckman, 2009), as an adhocracy (Konieczny, 2010), a potential anarchy (Viégas et al., 2007), and an oligarchy (Konieczny, 2009; Hill & Shaw, 2014). In my experience, understanding the governance of Wikipedia is similar to learning the rules of a child's game: the rules exist and are recited in detail, but they are also applied inconsistently and subject to change without warning. Wikipedians themselves describe their system of governance as consisting of "a mix of anarchic, despotic, democratic, republican, meritocratic, plutocratic, technocratic, and bureaucratic elements" (Wikimedia Foundation Board of Trustees as quoted in Kostakis, 2010).

The Five Pillars

Wikipedia is guided by five underlying principles called *the five pillars*—principles that inform and undergird the prevailing epistemic and social norms and practices for Wikipedia participation and

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[19] See https://en.wikipedia.org/wiki/Wikipedia:Wikipedia_Signpost/2014-07-09/News_and_notes

[20] See https://en.wikipedia.org/wiki/Wikipedia:Wikipedia_Signpost/2014-08-13/News_and_notes

[21] Wikipedian Molly White (User:GorillaWarfare) created an interactive timeline of Wikimedia-related events from 2014-2016, focusing on how the WMF had "suffered from lack of communication with the editing community, poor transparency, and sudden loss of staff members." See http://mollywhite.net/wikimedia-timeline/

contributions. The first draft of the five pillars was created on May 4, 2005. This draft describes the principles as “five unchangeable pillars that define Wikipedia’s character.” Several of the values expressed in the five pillars were articulated by Larry Sanger before Wikipedia was founded. For example, Sanger notes he’s “fairly sure” one of the first policies he and Wales agreed upon was “a ‘nonbias’ or neutrality policy” (Sanger, 2005). In fact, the five pillars have changed very little since 2005.

As of March 2019, the five pillars read:

> **Wikipedia is an encyclopedia.**
> It combines many features of general and specialized encyclopedias, almanacs, and gazetteers. Wikipedia is not a soapbox, an advertising platform, a vanity press, an experiment in anarchy or democracy, an indiscriminate collection of information, or a web directory. It is not a dictionary, a newspaper, or a collection of source documents, although some of its fellow Wikimedia projects are.
>
> **Wikipedia is written from a neutral point of view.**
> We strive for articles that document and explain the major points of view, giving due weight with respect to their prominence in an impartial tone. We avoid advocacy and we characterize information and issues rather than debate them. In some areas there may be just one well-recognized point of view; in others, we describe multiple points of view, presenting each accurately and in context rather than as “the truth” or “the best view”. All articles must strive for verifiable accuracy, citing reliable, authoritative sources, especially when the topic is controversial or is on living persons. Editors’ personal experiences, interpretations, or opinions do not belong.
>
> **Wikipedia is free content that anyone can use, edit, and distribute.**
> Since all editors freely license their work to the public, no editor owns an article and any contributions can and will be mercilessly edited and redistributed. Respect copyright laws, and never plagiarize from sources. Borrowing non-free media is sometimes allowed as fair use, but strive to find free alternatives first.
>
> **Editors should treat each other with respect and civility.**
> Respect your fellow Wikipedians, even when you disagree. Apply Wikipedia etiquette, and don't engage in personal attacks. Seek consensus, avoid edit wars, and never disrupt Wikipedia to illustrate a point. Act in good faith, and assume good faith on the part of others. Be open and welcoming to newcomers. If a conflict arises, discuss it calmly on the nearest talk pages, follow dispute resolution, and remember that there are 5,550,509 articles on the English Wikipedia to work on and discuss.
>
> **Wikipedia has no firm rules.**
> Wikipedia has policies and guidelines, but they are not carved in stone; their content and interpretation can evolve over time. Their principles and spirit matter more than their literal wording, and sometimes improving Wikipedia requires making an exception. Be bold but not reckless in updating articles, and do not agonize about making mistakes. Every past version of a page is saved, so any mistakes can be easily corrected.

Wikipedia’s governance as expressed in these pillars has a political dimension in at least two respects. First, the pillars explicitly convey certain values in the way they conceptualize and communicate norms for interactions between community members (i.e., “Respect your fellow Wikipedians, even when you disagree.”). And these explicitly expressed values represent an avowed commitment to particular political values—including a number of commonly held liberal democratic ideals like the value of open and free discourse and diversity in participation. Second, and as with any other reasonably complex social institution, Wikipedia’s institutional and practical structure implicitly express and endorse a set of values about who ought to participate in its knowledge-production process and what constitutes a legitimate contribution. For example, the second pillar includes the following statement: “Editors’ personal experiences, interpretations, or opinions do not belong.” But if text requires interpretation (Stout, 1982), whose interpretation determines neutral point of view?

Beyond the five pillars and for the purposes of this study, it is also important to know:

- Wikipedia has hundreds of policies, guidelines, and essays (the latter are informal pieces of writing about the former);
- Wikipedians occupy a range of positions and some have different permissions and responsibilities than others (see Figure 1.3);
- Wikipedians who act as administrators, bureaucrats, and Arbitration Committee members have additional permissions and responsibilities; Arbitration Committee members must run for their positions and be elected by the community;
- Editors (i.e., Wikipedians who do not have special permissions) generally try to resolve conflicts amongst themselves, escalating issues to administrators and then to the Arbitration Committee when they cannot reach consensus[22];
- Wikipedians—even those involved in governance—are unpaid volunteers.[23]

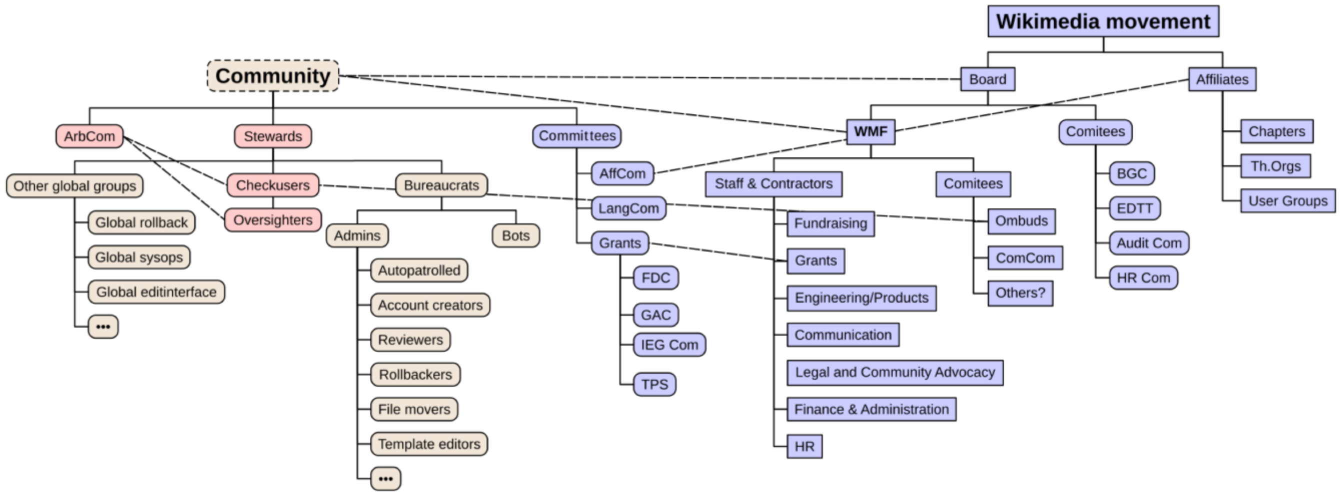

Figure 1.3. Wikimedia organizational and user rights hierarchy by PiRSquared17 (August 2014).

These basics about Wikipedia's governance provide context for situating what follows in this dissertation. For readers interested in learning more about Wikipedia's governance, I recommend Ayers, Matthews & Yates (2008) and Forte & Bruckman (2008).

Infrastructure

Wikipedia is built on wiki software, specifically MediaWiki, which enables it to be *wiki*—a collaboratively authored website users can modify directly from their web browsers. What is special about MediaWiki is that it is a free and open software package written in PHP and made available for

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[22] The concept of consensus—which does not mean unanimity or the result of a vote—is essential to understanding how conflicts are *ideally* resolved on Wikipedia. To learn more about consensus on Wikipedia, see Kriplean et al. (2007), Forte & Bruckman (2008), Butler, Joyce & Pike (2008), and—for a critical perspective—Peake (2015).

[23] Paid editing is a controversial topic on Wikipedia. The policy states that editors must disclose who their employers are and clearly state on their user page, in their article and talk page edit summaries, and on any related article talk pages that they are being compensated for their contributions.

download to anyone who wants to use it to create a wiki. So, one could download and use MediaWiki to create a wiki for the Information School at the University of Washington or a site about feminism like Geek Feminism Wikia.[24] What is special about Wikipedia is that, while it is built on MediaWiki, it is so highly customized that the majority of the features and functionalities of Wikipedia are, as Geiger (2014) notes, *bespoke code*: "code that runs alongside a platform or system, rather than being integrated into server-side codebases by individuals with privileged access to the server" (p. 342). Geiger further observes that Wikipedia's technical infrastructure resembles a city more than it does a singular building. For example, while the Foundation runs MediaWiki as their main web application, they also use Linux Virtual Server, Swift, MariaDB, and their own monitoring system PyBal (among others; see Figure 2.3). They currently have servers in data centers in California, Texas, and Virginia and in the Netherlands and Singapore, and while there is no longer a current publicly available list of all servers and nodes, a page on Phabricator—a web-based collaborative software development tool—lists several hundred nodes.[25]

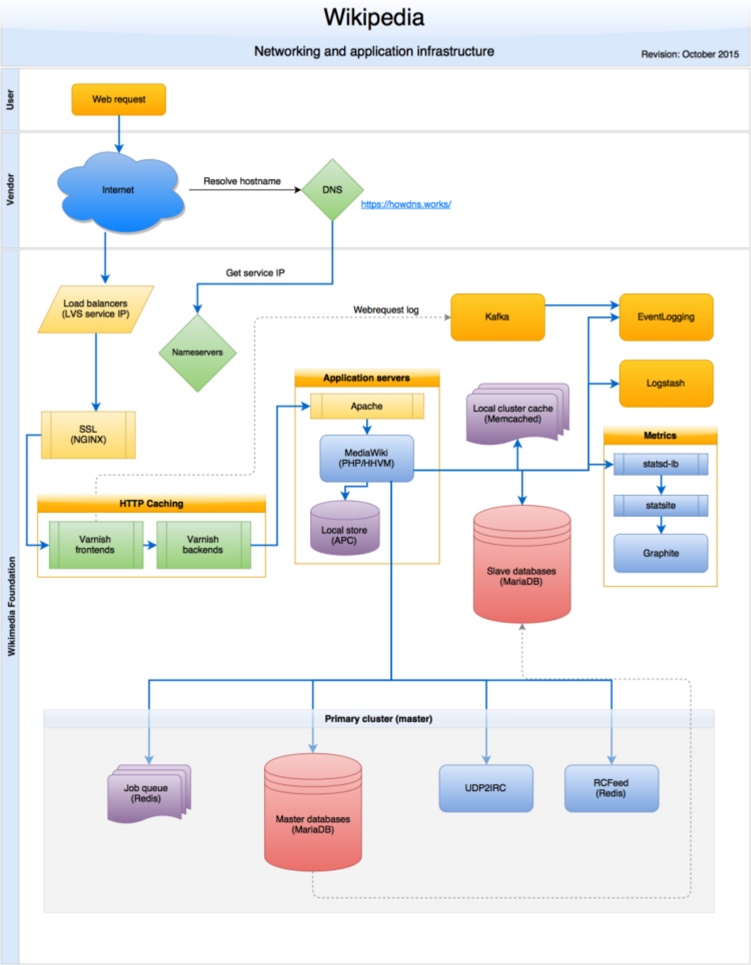

Figure 2.3. Diagram by Timo Tijhof detailing the life of a Wikipedia webrequest inside Wikimedia Foundation infrastructure as of October 2015.

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[24] Geek Feminism Wikia (http://geekfeminism.wikia.com/wiki/Geek_Feminism_Wiki) and other Wikia sites use a fork of MediaWiki and a variety of extensions.

[25] See https://phabricator.wikimedia.org/source/operations-puppet/browse/production/manifests/site.pp

All of these elements contribute to a corresponding social infrastructure. As Christian Sandvig (2013, p. 93), citing Bateson, writes:

> […] a key implication of this relational framing of infrastructure is that it represents 'an infinite regress of relationships' (Bateson, 1978:279). This means that there is no particular point in the sequence of infrastructure where things stop being social and become purely technical (or vice–versa).

Similarly, as my colleagues and I discovered (Menking, Erickson & Pratt, 2019), Wikipedia—the site and the community—consists of many different spaces, a fact often overlooked by researchers. Some of these spaces are determined by material differences in the ways Wikipedia actively construes itself across both digital and physical worlds. First, Wikipedia consists of:

- mailing lists;
- Wikipedia email;
- Internet relay chat (IRC);
- different namespaces on Wikipedia (e.g., an article, an article talk page, a user page, a user talk page);
- edit-a-thons, events where editors create and/or improve a specific type of content;
- hackathons, sprint-like events in which people involved in software development work on specific projects;
- Wikimania, the annual conference for Wikimedians;
- smaller annual conferences such as WikiConference North America;
- chapter meetings, independent organizations of Wikimedians who meet locally;
- workshops;
- and meet-ups.

Each of these subspaces possesses a different character as well as a different material identity. These characterological differences affect the cultures associated with each of these spaces, which gives rise to different types of interactions among the Wikipedians who engage there. For example, IRC tends to be devoted to technical conversations or used as real-time side channel (e.g., to monitor recent changes as noted by Steiner, Hooland & Summers, 2013) while chapter meetings occur offline and are generally devoted to socializing and chapter business such as budget discussions or planning outreach events or edit-a-thons. All of these subspaces shape Wikipedia, the website, and are inextricably tied to both the technical and social infrastructures that enable its success.

Second, these spaces are porous; interactions bleed across them, sometimes without the consent or control of Wikipedians. To continue Geiger's analogy of Wikipedia as a city rather than a singular building, we can imagine that some of Wikipedia's subspaces run through the community like roads, fiber cables, and sewer lines. At times these spaces overlap with each other requiring members of the community to make decisions about which system has the right-of-way and, consequently, who may be impacted. Take, for example, the cases of the Visual Editor and the "superprotect" feature presented above.

Finally, Wikipedia is inextricably connected to its 'sister projects'. For example, images included in an article on EN Wikipedia are—with a few exceptions (e.g., album cover art, which is hosted directly on

Wikipedia)—first uploaded to and appropriately licensed on Wikimedia Commons (see Chapter 5). While this study focusses solely on EN Wikipedia and Wikipedia's sister projects are out of scope, an awareness of the interconnected nature of the underlying technical infrastructure of Wikipedia and other Wikimedia sites is helpful for contextualizing the object biographies that follow in Chapters 6 and 7. As Slattery (2009) notes, it is important to understand the relationship between the built environment—which in Wikipedia's case is a sprawling, organic, and multidimensional—and the activities it supports.

Community

As I mentioned above, there is a wealth of research about Wikipedia's community. Here, I focus on research related to participatory and content gaps.[26] I have chosen to focus on this body of work because of its relevance to this study's final research question: *In what ways do participatory gaps (e.g., gender, age, race) on the English language Wikipedia shape women's health information on the site?*

Participatory Gaps

> While I don't think anyone has done a survey, I believe that Wikipedia runs at least 4-1 male; I haven't encountered any self-identified African-Americans, although I presume there are a few; I haven't encountered any self-identified Native Americans, although I presume there are at least a few people with significant Native American ancestry (although perhaps not who heavily identify with that ancestry). Also, there seems to be an age-bulge in roughly 18-40; my personal view is that for an encyclopedia, the lack of any large number of people younger than that is no calamity (the ones with the skills do find us), but the lack of those of us older can be, especially on political topics. There is a strong resulting bias toward the politics of the moment ratner [*sic*] than a longer-term view.
> 18:31, Sep 22, 2004 (UTC)[27]

Although Wikipedia is self-purportedly "the encyclopedia anyone can edit," there are several barriers to becoming a Wikipedian (Panciera, Halfaker & Terveen, 2009) or even making a contribution that is not soon reverted by others. Wikipedia's guidelines instruct editors not to "bite the newbies," but they also proclaim, "there are no rules," and community norms tend to reward aggressive behaviors (Choi et al., 2010; Halfaker, Kittur & Riedl, 2011). As Morgan and his colleagues (2013a) have noted, these cultural contradictions make it difficult for newcomers to participate and may dissuade women and members of other underrepresented groups from editing. For example, by best counts, more than 80% of Wikipedians are men (Hill & Shaw, 2013): a demographic skew that has come to be known as the *gender gap*.

Wikipedia's gender gap in participation first came into focus after the Collaborative Creativity Group at the United Nations University Maastricht Economic and Social Research Institute on Innovation and Technology (UNU-MERIT) partnered with the WMF to do a comprehensive survey of Wikipedia readers and contributors in 2008. Translated into 20 languages and completed with more than 170,000 responses, the survey found only 13% of Wikipedia contributors at that time were women (Hill & Shaw, 2013). Since then, this participatory gender gap—and its potential impact on content—has been both well publicized (e.g., LaVallee, 2009; Pappas, 2014; Kleeman, 2015; Paling, 2015; Torres, 2016; Sayej, 2018) and increasingly well researched (see Appendix A). In response to the UNU-MERIT survey, Sue Gardner, then Executive Director of the WMF, set a goal to increase women's participation in Wikipedia globally to 25% by 2015. The *New York Times* published an article about Gardner's

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[26] In Chapter 2, I review literature related to medical and health related information on Wikipedia.

[27] I have removed user names from online comments throughout, though I still include the date and time stamp.

intentions (Cohen, 2011), and she responded with a blog post entitled “Nine reasons women don’t edit Wikipedia (in their own words).” The reasons she cites include a lack of a user-friendly interface, a lack of discretionary time, a lack of self-confidence, an aversion to conflict, a misogynist atmosphere, and a sexually charged culture (Gardner, 2011).

Researchers have since tested many of Gardner’s claims. One of the earliest studies by Lam and his colleagues (2011) confirmed a gap in women’s participation and noted the percentage of women editing was not increasing over time. This study also reported that: (1) men and women focused on different content areas; (2) articles with a higher percentage of women editors were more likely to be protected (a range of states that prevent unregistered users or users without experience or administrator privileges from editing); (3) women were more likely to have their edits reverted and to leave the editing community as a consequence; and (4) the gender gap has a “detrimental effect” on content presumed to be of interest to women. Collier & Bear (2012) examined the UNU-MERIT survey data, proposing the gap may exist because women are less likely to engage in conflict, more likely to lack self-confidence, and less comfortable with criticism—both giving and receiving. Hargittai & Shaw (2015), relatedly, suggested women may be less likely to participate in Wikipedia due to a lack of Internet skills. Like parts of Gardner’s 2011 blog post, many of these findings situate the gender gap as a result of women having or not having specific traits or skills.

However, other studies have pointed to the ways in which women actively contribute to Wikipedia, making more significant revisions (Antin et al., 2011) and writing longer messages than men (Iosub et al., 2014). These findings counter arguments that women’s skills or traits alone determine their levels of participation. In addition, researchers such as Ford & Wajcman (2017) and Menking & Erickson (2015) have argued women Wikipedians persist despite “Wikipedia’s origins and the infrastructures on which it relies [being] based on foundational epistemologies that exclude women” (Ford & Wajcman, 2017). See Appendix A for a more comprehensive review of research about the participatory gender gap.

As the above 2004 comment from an editor indicates, in addition to the gender gap, Wikipedia evidences other participatory gaps. For example, researchers Mark Graham (Graham, 2011; Graham et al., 2015) and Heather Ford (2011; 2017) have documented and investigated geographical and cultural gaps while social activist groups like AfroCrowd and Black Lunch Table have begun to address racial gaps (Cassano, 2015; Lapowsky, 2015). Relatedly, the non-profit organization Whose Knowledge?, founded by two former Foundation employees, has worked closely with underrepresented groups including the Dalit community, queer and feminist archives in Bosnia and Herzegovina, and Kumayaay Native Americans to facilitate inclusive campaigns. However, many of these participatory gaps—specifically racial gaps—are currently understudied and undertheorized, particularly in comparison to the gender gap. This is, in part, due to the pseudonymous nature of Wikipedia’s community; apart from self-reported account data and survey data triangulated with data from in-person events, it is difficult to know *exactly* who edits Wikipedia. Furthermore, as Reagle (2013) and MacAulay & Visser (2016) have noted, the rhetoric of freedom, democracy, and diversity espoused by open source communities like Wikipedia and by organizations like the WMF may actually undermine real efforts to address participatory gaps in that it allows for the claim that certain people do not edit simply because they do not want to.

Content Gaps

Wikipedians, WikiProjects, activist groups, and industry partners have addressed content gaps by engaging in focused editing, recruiting new editors, and leveraging technology. For example, Primer, a technology startup, has used artificial intelligence (AI) and natural language processing (NLP) to identify scientists who have been covered in scientific studies and news articles but who do not have Wikipedia articles; the program, called Quicksilver, then creates draft articles (Liu et al., 2018). While these initiatives generate missing content, they rarely broaden the contributor base. Art + Feminism, a global campaign intended to encourage editors to address content gaps, is now in its sixth year, and though the campaign has resulted in the creation of thousands of new pages and attracted a large number of new editors, retention of participants remains challenging (Farzan, Savage & Saviaga, 2016).

Though the relationships between Wikipedia's participatory gaps and content gaps have not been empirically established as causal, many researchers have hypothesized a connection between the two. Wagner and her colleagues (2015) have assessed gender bias across multiple dimensions, finding that women are portrayed differently than men in Wikipedia biographies, and Graham and his colleagues (2015) have investigated geographical and socioeconomic patterns, noting that while the availability of broadband increases participation in Wikipedia, people from the economic margins still tend to contribute content about the world's economic cores rather than focusing on their own local regions. This last study (Graham et al., 2015), in particular, challenges the conflation of an editor's demographics with the content they choose to edit.

WikiProjects

A WikiProject (WP) is a group of Wikipedians who work together either to accomplish specific editing tasks (i.e., copyediting, assessing the quality of articles) or to create, edit, and maintain content related to a particular topic (e.g., mathematics, video games, women scientists). EN Wikipedia currently has over 2,000 such projects. Some of the largest and most active WPs include WP Biography, WP United States, and WP Military History. WP are instrumental in contributing to Wikipedia's success yet many of them—particularly those that are smaller and less active—are only loosely structured. Their boundaries are porous, and editors who are not explicit members often play important roles (Morgan et al., 2013b). Different WPs evidence different kinds of material identities as well as norms and practices. For example, some WPs use WikiProject X, a tool developed to streamline the design of projects largely by automating certain kinds of updates (i.e., using bots to populate sections like Discussions, Tasks, and Metrics). Other WPs customize wiki pages to brand themselves and establish their processes. Generally, WP pages are places where editors interested in a specific task or topic can coordinate work.

Below, I provide an overview of two WikiProjects that are particularly relevant to this dissertation work: WikiProject Women's Health and WikiProject Medicine.

WikiProject Women's Health

WikiProject Women's Health (WP Women's Health) was started in 2015, approximately 14 years after the English language Wikipedia was founded. According to the project page, it focuses on "articles related to women's health, including related social and political issues" (WikiProject Women's Health, n.d.). The project's logo features a simplified blue Rod of Asclepius superimposed over a dark pink Venus symbol (see Figure 3.3). WP Women's Health has adopted WikiProject X so that its pages are automatically updated by bots.

Figure 3.3. WikiProject Women's health logo.

As of March 2019, WP Women's Health consists of 17 explicit, active members and 16 explicit, inactive members, including me. (Explicit members are those who have signed up to the project; inactive members are those who have not edited within a month.)

WikiProject Medicine

In contrast to WP Women's Health, WikiProject Medicine (WP Medicine) was started in 2004, only three years after the English language Wikipedia was founded. According to the WP Medicine project page, the project is a place to "discuss, collaborate, and debate anything and everything relating to medicine and health on Wikipedia" (WikiProject Medicine, n.d.). As Shafee and his colleagues (2017) write about WP Medicine:

> WikiProject Medicine was one of the first such communities, being founded in 2004 by Jacob de Wolff, MD. It is also one of the most active (consistently in the top 10 […]) with 130 participants on its discussion forum in any given 90-day window, and a further 700 contributors who edit articles within its scope. The community's overall size has remained relatively constant since 2013. These are largely a mixture of health professionals, researchers and students with an interest in freely available, accurate medical information. […] The community has since expanded to form the Wiki Project Med Foundation, in 2012, a non-profit corporation working to promote the broader development and distribution of Wikipedia-related medical content.

WP Medicine has since partnered with Cochrane, Cancer Research UK, and medical schools, creating more than 40,000 articles and enlisting more than 80 active project members. Given its history and reach, it is perhaps not surprisingly that WP Medicine has received significant media and scholarly attention. In contrast, to date WP Women's Health has not been studied.

Articles as Information Objects

What is a Wikipedia article? According to Wikipedia, an article is a page on the site that has encyclopedic information. Each article can contain multiple types of information ranging from content to hyperlinks to metadata to images. Because Wikipedia is collaboratively authored, these articles are socially, culturally, historically, and politically situated and often serve as boundary objects for different stakeholders. Understandably, Wikipedia articles and their associated talk pages can be sites of discourse where we see epistemology in action. We might ask what it means for an article to be defined by Wikipedia as a page that has "encyclopedic information" and who decides what kinds of information are "encyclopedic."

In the case of a digital artifact like a Wikipedia article, I have adapted the method of object biography in this study to present the ways in which an information object can be assembled over time. Because each Wikipedia article is a dynamic product with numerous streams of digital traces, creating a data-based narrative to communicate the story of an article's life provides a different approach to understanding how participation interacts with content. For more information about object biography, please see Chapter 4.

The anatomy of an article

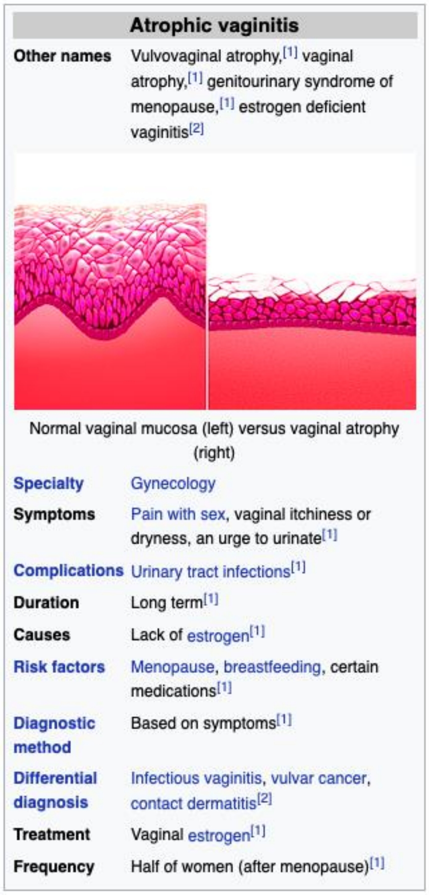
While most readers are likely familiar with a Wikipedia article, understanding the anatomy of both a Wikipedia article and a Wikipedia article page is crucial to understanding the object biographies I have included in following chapters. Here, I outline the anatomy of a Wikipedia article and of a Wikipedia article page from the perspective of a user who is not logged into Wikipedia. I have chosen to annotate an EN Wikipedia article and article page because the object biographies that follow are the stories of English language articles. However, there are differences in article and article page properties depending on whether the user is logged into Wikipedia and which language Wikipedia she is accessing.

Title

The title of an article not only proceeds the content of that article, it also determines the article's page name (e.g., a term used to refer to any page sent from a Wikipedia database) and URL. While a title may seem like a straightforward component of an article, it is important to note that the title a user sees has been assigned by Wikipedia editors, and a user may not come to it directly. That is, if one uses Wikipedia's native search feature to look for a topic, she may be automatically redirected to a page with a title that differs from the search term. This may also happen if a user searches for a term via a popular search engine like Google or via her browser's URL bar. I point this out to underscore the social construction of Wikipedia: there is a relationship between objects and humans on Wikipedia that is often opaque to users who are not contributors to the system. The title a user sees may be the result of lengthy debate. For example, on the English language Wikipedia, there is a policy dedicated to assigning article titles.

Infobox

An infobox is a panel that appears near the top right of the article (when viewed via a desktop browser; the infobox appears after the lead paragraph when viewed via a mobile browser); in it, key facts are summarized. Infoboxes are also socially constructed and not automatically generated. (See Figure 4.3.)



Atrophic vaginitis	
Other names	Vulvovaginal atrophy,[1] vaginal atrophy,[1] genitourinary syndrome of menopause,[1] estrogen deficient vaginitis[2]

Normal vaginal mucosa (left) versus vaginal atrophy (right)

Specialty	Gynecology
Symptoms	Pain with sex, vaginal itchiness or dryness, an urge to urinate[1]
Complications	Urinary tract infections[1]
Duration	Long term[1]
Causes	Lack of estrogen[1]
Risk factors	Menopause, breastfeeding, certain medications[1]
Diagnostic method	Based on symptoms[1]
Differential diagnosis	Infectious vaginitis, vulvar cancer, contact dermatitis[2]
Treatment	Vaginal estrogen[1]
Frequency	Half of women (after menopause)[1]

Figure 4.3. An example of an infobox taken from the Atrophic vaginitis article. Note that the text in blue denotes a wikilink—a hyperlink to another Wikipedia article or page. For example, "Specialty" links to the Wikipedia article for "Specialty (medicine)." This infobox uses a template called "Infobox medical condition" which includes 23 possible fields but does not require that the user complete all of the fields.

Lead

The lead (or lede) paragraph of a Wikipedia article is the first paragraph of the article. It appears before the table of contents and the first heading. According to Wikipedia's Manual of Style (MoS), the lead paragraph should provide a summary of the article and "cultivate interest in reading on," but it should not be sensational or a "news-style lede." Article leads often inform intelligent assistant responses. For example, if one asks Siri, "What is feminism?", Siri will read the lead paragraph of the Wikipedia article *Feminism*.

Table of contents

The table of contents for the article appears as a hyper-linked panel near the top left of the article. A table of contents for an article with four or more headings is automatically generated.

Body

The body of a Wikipedia article may range in size, depth, and quality (not mutually inclusive) from a stub—according to Wikipedia, “an article deemed too short to provide encyclopedic coverage of a subject”—to a Featured Article, an article “considered to be some of the best articles Wikipedia has to offer, as determined by Wikipedia’s editors.”

References

The References section of an article follows the body and is usually preceded by a heading such as “Notes” or “References.” References are selected and curated by Wikipedians. Because Wikipedia is an encyclopedia, it does not publish or cite original research. Wikipedia’s verifiability policy requires in-line citations for direct quotes and any material that’s likely to be challenged.

Categories

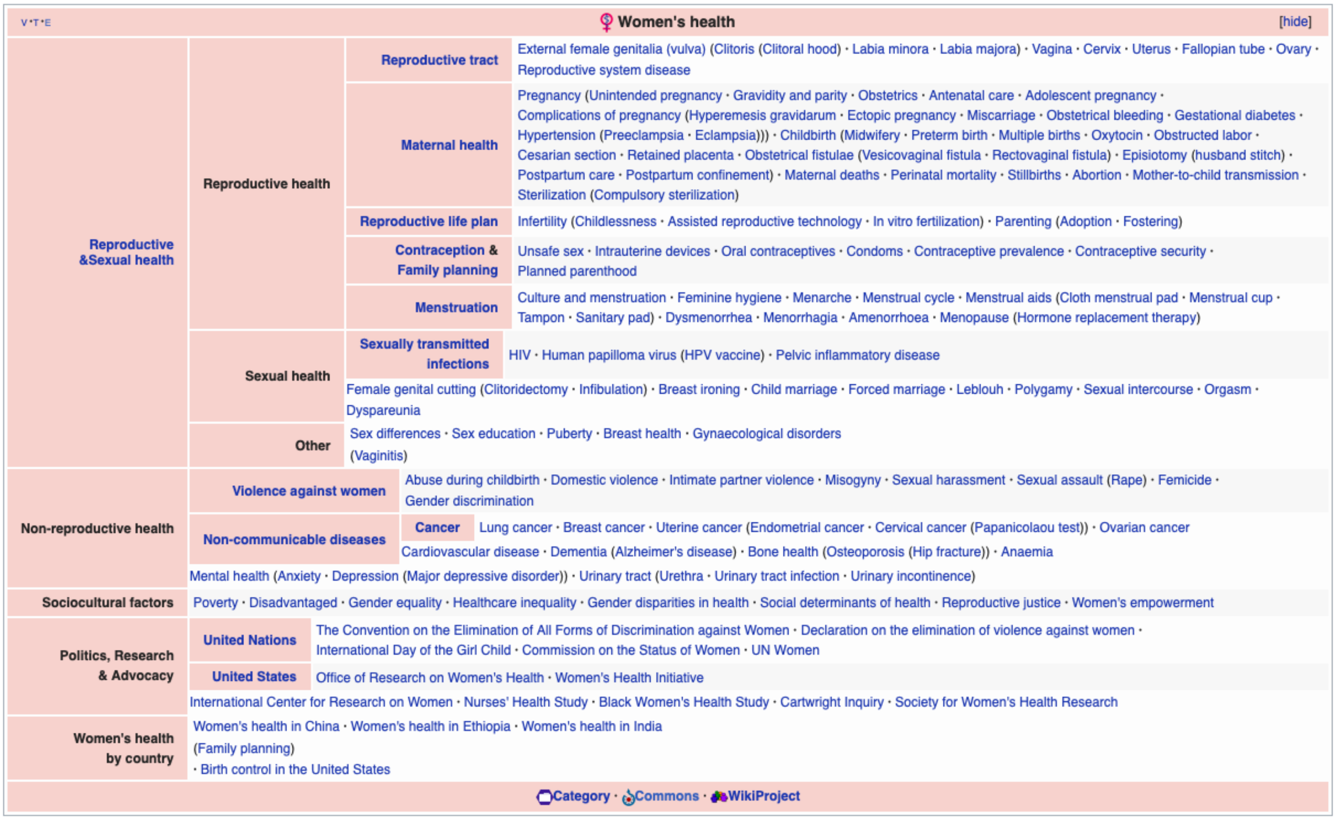
Wikipedians assign categories to every article in Wikipedia. Some of these categories are visible to the reader. For example, topical categories *Category:France* and sub-topical categories like *Category:Cities in France* are visible to readers; however, administrative categories like *Category:Infobox medical condition (new)* are hidden from readers on the article page but can be seen via Page information. See Figure 5.3

Wikilinks

Wikilinks are hyperlinks within Wikipedia. The more hyperlinks in an article, the more it is connected to other Wikipedia content. Wikilinks are created by Wikipedia editors.

Images

For an image to be included in a Wikipedia article, it must first be uploaded to Wikimedia Commons and licensed for use unless the community has decided to make an exception. If an exception has been granted—say, as it has been in the case of album cover art under fair use—then Wikipedia can host the image directly, bypassing Commons. Images in Wikimedia Commons may be used on any language Wikipedia. Wikipedia’s Manual of Style outlines how images should be chosen and used. Notably, Wikipedia is not censored, so articles may include potentially offensive or vulgar images if the community agrees that the image improves the encyclopedic relevancy or accuracy of the information in the article. Articles with images are often considered to be of higher quality.



V·T·E ♀ **Women's health** [hide]

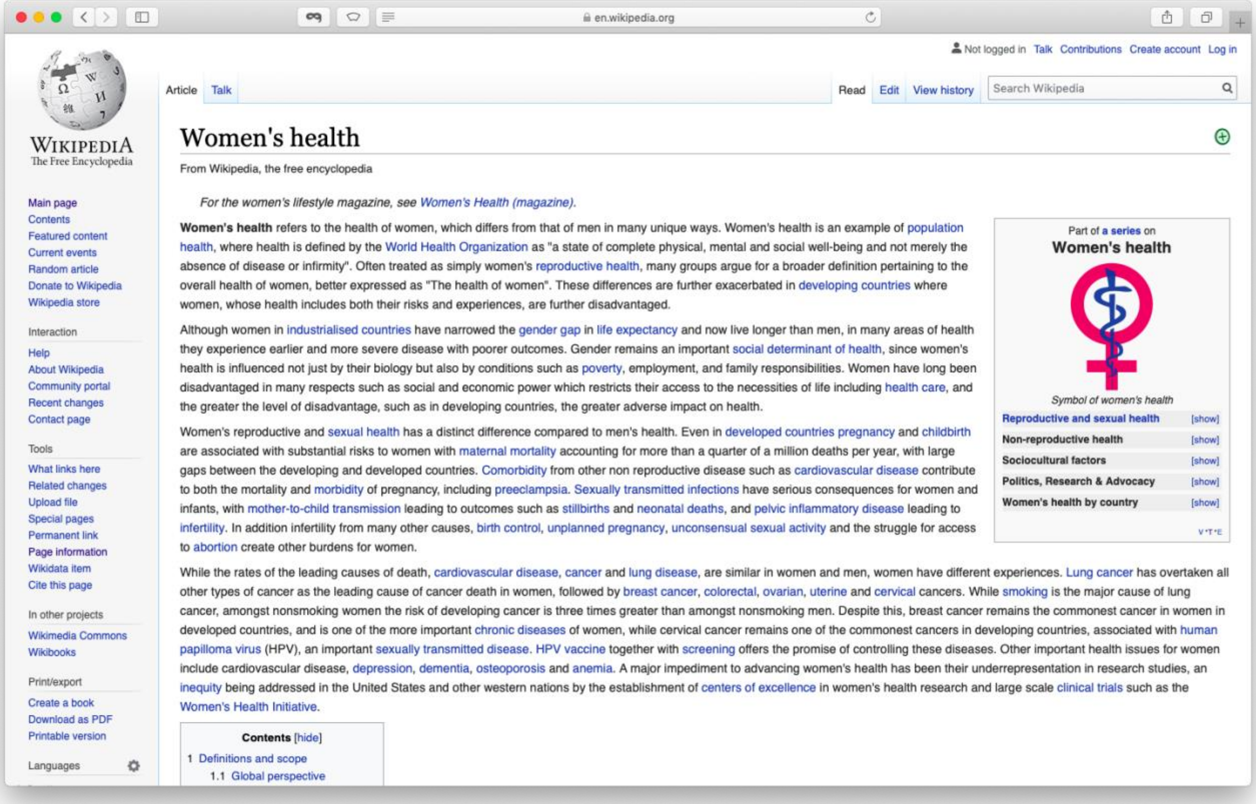
Reproductive &Sexual health	**Reproductive health**	**Reproductive tract**	External female genitalia (vulva) (Clitoris (Clitoral hood) · Labia minora · Labia majora) · Vagina · Cervix · Uterus · Fallopian tube · Ovary · Reproductive system disease
		Maternal health	Pregnancy (Unintended pregnancy · Gravidity and parity · Obstetrics · Antenatal care · Adolescent pregnancy · Complications of pregnancy (Hyperemesis gravidarum · Ectopic pregnancy · Miscarriage · Obstetrical bleeding · Gestational diabetes · Hypertension (Preeclampsia · Eclampsia))) · Childbirth (Midwifery · Preterm birth · Multiple births · Oxytocin · Obstructed labor · Cesarian section · Retained placenta · Obstetrical fistulae (Vesicovaginal fistula · Rectovaginal fistula) · Episiotomy (husband stitch) · Postpartum care · Postpartum confinement) · Maternal deaths · Perinatal mortality · Stillbirths · Abortion · Mother-to-child transmission · Sterilization (Compulsory sterilization)
		Reproductive life plan	Infertility (Childlessness · Assisted reproductive technology · In vitro fertilization) · Parenting (Adoption · Fostering)
		Contraception & Family planning	Unsafe sex · Intrauterine devices · Oral contraceptives · Condoms · Contraceptive prevalence · Contraceptive security · Planned parenthood
		Menstruation	Culture and menstruation · Feminine hygiene · Menarche · Menstrual cycle · Menstrual aids (Cloth menstrual pad · Menstrual cup · Tampon · Sanitary pad) · Dysmenorrhea · Menorrhagia · Amenorrhoea · Menopause (Hormone replacement therapy)
	Sexual health	**Sexually transmitted infections**	HIV · Human papilloma virus (HPV vaccine) · Pelvic inflammatory disease
			Female genital cutting (Clitoridectomy · Infibulation) · Breast ironing · Child marriage · Forced marriage · Leblouh · Polygamy · Sexual intercourse · Orgasm · Dyspareunia
	Other		Sex differences · Sex education · Puberty · Breast health · Gynaecological disorders (Vaginitis)
Non-reproductive health	**Violence against women**		Abuse during childbirth · Domestic violence · Intimate partner violence · Misogyny · Sexual harassment · Sexual assault (Rape) · Femicide · Gender discrimination
	Non-communicable diseases	**Cancer**	Lung cancer · Breast cancer · Uterine cancer (Endometrial cancer · Cervical cancer (Papanicolaou test)) · Ovarian cancer
			Cardiovascular disease · Dementia (Alzheimer's disease) · Bone health (Osteoporosis (Hip fracture)) · Anaemia
			Mental health (Anxiety · Depression (Major depressive disorder)) · Urinary tract (Urethra · Urinary tract infection · Urinary incontinence)
Sociocultural factors			Poverty · Disadvantaged · Gender equality · Healthcare inequality · Gender disparities in health · Social determinants of health · Reproductive justice · Women's empowerment
Politics, Research & Advocacy	**United Nations**		The Convention on the Elimination of All Forms of Discrimination against Women · Declaration on the elimination of violence against women · International Day of the Girl Child · Commission on the Status of Women · UN Women
	United States		Office of Research on Women's Health · Women's Health Initiative
			International Center for Research on Women · Nurses' Health Study · Black Women's Health Study · Cartwright Inquiry · Society for Women's Health Research
Women's health by country			Women's health in China · Women's health in Ethiopia · Women's health in India (Family planning) · Birth control in the United States

Category · Commons · WikiProject

Figure 5.3. An example of category designations from the Women's health article. Note that the text in blue denotes a wikilink. Categories on Wikipedia are manually assigned by editors and, subsequently, Wikipedia's ontology is often described as a folksonomy (Strube & Ponzetto, 2006).

The anatomy of an article page

While a Wikipedia article takes up the majority of space and, perhaps, attention on a Wikipedia article page, there are several important aspects of the page itself that contribute to and create a very specific kind of information object.



Women's health

From Wikipedia, the free encyclopedia

For the women's lifestyle magazine, see Women's Health (magazine).

Women's health refers to the health of women, which differs from that of men in many unique ways. Women's health is an example of population health, where health is defined by the World Health Organization as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". Often treated as simply women's reproductive health, many groups argue for a broader definition pertaining to the overall health of women, better expressed as "The health of women". These differences are further exacerbated in developing countries where women, whose health includes both their risks and experiences, are further disadvantaged.

Although women in industrialised countries have narrowed the gender gap in life expectancy and now live longer than men, in many areas of health they experience earlier and more severe disease with poorer outcomes. Gender remains an important social determinant of health, since women's health is influenced not just by their biology but also by conditions such as poverty, employment, and family responsibilities. Women have long been disadvantaged in many respects such as social and economic power which restricts their access to the necessities of life including health care, and the greater the level of disadvantage, such as in developing countries, the greater adverse impact on health.

Women's reproductive and sexual health has a distinct difference compared to men's health. Even in developed countries pregnancy and childbirth are associated with substantial risks to women with maternal mortality accounting for more than a quarter of a million deaths per year, with large gaps between the developing and developed countries. Comorbidity from other non reproductive disease such as cardiovascular disease contribute to both the mortality and morbidity of pregnancy, including preeclampsia. Sexually transmitted infections have serious consequences for women and infants, with mother-to-child transmission leading to outcomes such as stillbirths and neonatal deaths, and pelvic inflammatory disease leading to infertility. In addition infertility from many other causes, birth control, unplanned pregnancy, unconsensual sexual activity and the struggle for access to abortion create other burdens for women.

While the rates of the leading causes of death, cardiovascular disease, cancer and lung disease, are similar in women and men, women have different experiences. Lung cancer has overtaken all other types of cancer as the leading cause of cancer death in women, followed by breast cancer, colorectal, ovarian, uterine and cervical cancers. While smoking is the major cause of lung cancer, amongst nonsmoking women the risk of developing cancer is three times greater than amongst nonsmoking men. Despite this, breast cancer remains the commonest cancer in women in developed countries, and is one of the more important chronic diseases of women, while cervical cancer remains one of the commonest cancers in developing countries, associated with human papilloma virus (HPV), an important sexually transmitted disease. HPV vaccine together with screening offers the promise of controlling these diseases. Other important health issues for women include cardiovascular disease, depression, dementia, osteoporosis and anemia. A major impediment to advancing women's health has been their underrepresentation in research studies, an inequity being addressed in the United States and other western nations by the establishment of centers of excellence in women's health research and large scale clinical trials such as the Women's Health Initiative.

Figure 6.3. A screenshot of the Women's health article page. Note the infobox on the top-right hand side of the article, the tabs for Talk, Edit, and View History, and the Tools menu on the left-hand side of the page. This is a view of an article page without logging into the system.

Tools

A menu runs the length of the left-hand side of a Wikipedia article. Included in this menu is a section with the heading Tools. There are eight hyperlinks in this section, including: What links here, Related changes, Upload file, Special pages, Permanent link, Page information, Wikidata item, and Cite this page. Two of these links (Upload file and Special pages) are universal; that is, they are not specific to the Wikipedia article featured on the Wikipedia article page one is viewing. The other six links are specific to the Wikipedia article. Page information and Wikidata item are particularly helpful when studying articles as information objects. (See Figure 6.3.)

Talk

Every article page on Wikipedia has a space for a talk page, even a talk page that has yet to be created. The talk page is the place where editors discuss the article. Talk pages can consist of several components including templates that indicate which WikiProjects are interested in the article, archives of older talk pages, contents, comments and replies, and categories.

Edit

Every Wikipedia article page features an edit option. All users—whether or not they are registered—can edit a Wikipedia article in principle. In practice, many articles are protected in some way. (Protection ranges from fully-protected—a page can be edited or moved only be administrators—to semi-protected—a page cannot be edited by unregistered users or by users whose accounts are new.) By default, when an unregistered user clicks Edit, she is presented with a pop-up window welcoming her to Wikipedia and providing the option to switch to the Visual Editor or to start editing using wiki markup.

View history

Every user can view the revision history of an article, which includes the date and time of each edit, the user names or IP addresses of the users who have made changes to the article, the number of bytes added or subtracted, and an edit summary if available. View history also allows users to compare different revisions and to see tags automatically applied to some edits (e.g., "Minor edit"). Wikipedia has many more components, tools, and features beyond those outlined above, but a familiarity with the ones listed here provides a background for understanding what follows in Chapters 5-7.

Summary

I have chosen the English language Wikipedia as a site of study for several reasons, many of which are practical and some of which I discuss in more detail in Chapter 4. First, I am fluent in English and am located in the United States. Second, as discussed above, the EN Wikipedia is the oldest and largest, evidencing unique participatory and content gaps and increasingly connected to other information systems. Third, over the past five years, I have become invested in the virtual and physical worlds of Wikipedia. I have created and edited EN Wikipedia articles, co-hosted and participated in edit-a-thons, attended local chapter meetings, applied for and received a research grant from the WMF, served on a grants committee for the WMF, written posts for the WMF's online newsletter (Menking, 2014; Menking, 2015), subscribed and contributed to mailing lists, been a member of private Facebook groups for women Wikipedians, become friends with former and current WMF employees, served on the advisory board of Whose Knowledge?, uploaded images to Wikimedia Commons, and joined and participated in WikiProjects.

While limiting my site of research to only one *site* may seem irresponsible or naïve (multi-sited ethnographies, particularly in our age of globalism, are increasingly common), the goal of this inductive, qualitative study is to attend to the richness and depth of the English language Wikipedia as a sociotechnical system. Thus, this study takes up multiple strands of data from a range of times, spaces, and places. The English language Wikipedia as a *phenomenon* is a dynamic and complex site of study beyond en.wikipedia.org—one perfectly suited to investigating questions about women's health information online, expertise, evidence, and knowledge production.

Chapter 4: Methodology

Introduction

> Be patient toward all that is unsolved in your heart and try to love the questions themselves, like locked rooms and like books that are now written in a very foreign tongue.
>
> Rainer Maria Rilke, 1929

A researcher's choice of methods can disclose her methodology, paradigm, and epistemology (Aguinaldo, 2004). Qualitative methods, for example, depend on foregrounding the researcher as a tool of analysis and are intended to provide "an interpretive and naturalistic approach to the world" (Denzin & Lincoln, 2005, p. 3). Generally, qualitative methods are associated with social constructionist, deconstructionist, and postmodern paradigms; that is, researchers using qualitative methods are assumed to believe in subjective reality and to assert that they cannot fully know this reality as they continually construct (or deconstruct) it. Weick (2007) asserts that the "richness" of qualitative data can "restrain hubris" (p. 18) by giving "elapsed events their own present" (p. 17) and by preserving contradictory narratives as well as ambiguities—all of which "enlarge our understanding of the human condition" (p. 18). In short, qualitative researchers value context and complexity.

One of the many advantages of using qualitative methods to study a sociotechnical system like Wikipedia is that they allow us to understand better how the users of a system make sense of their actions and activities as well as how they make sense of the system itself. Another advantage of using qualitative methods is that they can provide rich descriptions of complex phenomena as they occur within specific, localized contexts. Finally, qualitative methods are often the most helpful approach when little is known about a given phenomenon (the three qualitative studies mentioned above are relatively early in terms of Wikipedia research) or when quantitative studies have raised questions that cannot be answered by quantitative methods. For example, in my own work I have been curious about what quantitative studies of the participatory gender gap on Wikipedia do not say and the questions they have left unanswered. For this reason, I have spent the past five years conducting ethnographic research to investigate the participatory gender gap from the perspectives of women who are involved in local chapters, work at the Wikimedia Foundation, edit Wikipedia, contribute to Wikipedia's sister projects, and sometimes decide to leave the movement (Menking & Erickson, 2015; Menking, Erickson & Pratt, 2019).

Similarly, the purpose of this inductive, qualitative dissertation is twofold: (1) to answer research questions that cannot be easily answered using quantitative methods and (2) to interrogate an understudied topical domain on Wikipedia: women's health. Thus, I ask the following:

> *How do Wikipedians who edit women's health content perceive women's health information on the English language Wikipedia? Why do they write it? How do they envision their audiences? What do they think is missing?*
>
> *What can object biographies tell us about the production and neglect of women's health information in sociotechnical systems like the English language Wikipedia? What can they tell us about the reproduction of scientific knowledge related to women's health in public spheres like the English language Wikipedia?*

> *In what ways do participatory gaps (e.g., gender, age, race) on the English language Wikipedia shape women's health information on the site?*

To answer these questions, I designed a dissertation project drawing from five years of ethnographic research. I have also conducted semi-structured interviews (n=15) with Wikipedians who explicitly identify as members of WikiProject Women's Health and/or who have edited women's health content; relatedly, I have performed document analysis of a selection of article and project talk pages (n=16) relevant to this WikiProject. Finally, drawing from these interviews, article revision histories, talk page discussions, trace data, and participant observation, I have adapted the method of object biography to write the life-history of a selection of women's health articles (n=5).

In the following sections, I outline how ethnographic research informed the design of this study. I then describe my stance as a researcher, including how I came to research Wikipedia and gain access to the community. Next, I describe how I collected and analyzed data for each of the methods I used. I then discuss how this dissertation work should be evaluated. Finally, I provide a summary of the chapter.

Ethical Considerations

I begin by addressing ethical considerations. I obtained Institutional Review Board (IRB) approval from the University of Washington before recruiting participants for this study (see Appendix B). I provided all participants with study information (see Appendix D) and asked they (1) acknowledge they were 18 years of age or older and (2) provide either verbal or written consent. I offered participants compensation in the form of Amazon gift cards ($25 per physical card) funded by the University of Washington Information School's doctoral dissertation grant. One participant declined compensation, and one requested I donate the same amount to a charity that benefits homeless women. In the latter case, I donated $25 to Mary's Place, a nonprofit organization in Seattle that offers shelter and services to women, children, and families facing homelessness. I sent two gift cards (totaling $50) to participants with whom I spent more than 60 minutes.

I maintain that participants own their data (DeVault & Gross, 2007); thus, I invited them to review their transcripts to provide comments and redact content. Two participants asked to redact content, and I have honored their requests in the chapters that follow. As Kim TallBear (2014) writes, "It is [...] helpful to think creatively about the research process as a relationship-building process […] as an opportunity for conversation and sharing of knowledge, not simply data gathering" (p. 2). TallBear also differentiates between giving back and "standing with." My aim in this dissertation work is to do the latter: to stand with participants, recognizing them as experts. Although I do not always agree with their perspectives, and my analysis, in many cases, has provided a different way of viewing the data in aggregate, I try to center their voices, expertise, and lived experiences.

With the exception of deletion logs[28], the data I collected from Wikipedia is all public data and relatively easy to access. However, Wikipedia is, in many ways, a "small world" (Burnett, Besant, & Chatman, 2001). For example, Wikipedians who specialize in a certain kind of work (e.g., vandal-fighting, reverting copyright violations), contribute to only one domain (i.e., women's health articles), or perform a specific role (e.g., Arbitration Committee member, Wikipedian in Residence) are often easy to

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[28] The deletion logs I accessed are public but accessing them requires scripting or use of the Wikimedia Foundation's public querying tool, Quarry.

identify. Additionally, because almost every action and interaction on Wikipedia results in a public digital trace, non-Wikipedians can easily connect the dots between snippets of anecdotes, articles, and editors. Because of these aspects of Wikipedia research, I have used pseudonyms for interviewees, and I do not include any Wikipedia usernames in this document, even for those editors who are not directly involved in my study (with the exception of crediting users who created images). I have also sought to protect participants as much as possible by sharing limited demographic information and by removing contextual information whenever possible.

Ethnographic Research

> Ethnography has always been tough. […] There are few shortcuts and no ways to learn one's way around an unfamiliar social world without being there and banking on the kindness of strangers.
>
> John Van Maanen, 2011

This dissertation work is not exactly an ethnography, but it would not have been possible without ethnographic research. The aim of ethnographic research is to understand everyday life and human experience in context; ethnography, as Van Maanen (2011) writes, is "the study and representation of culture as used by particular people, in particular places, at particular times" (p. 155). Most often associated with disciplines like anthropology and sociology, ethnography has been adopted by social science scholars in various disciplines, including communications, science and technology studies, and human-computer interaction. While definitions and uses of ethnographic research differ and are often debated (see Dourish, 2006) across disciplinary boundaries, there are at least three key elements of ethnographic research that tend to persist and that were essential for this study: participant observation, "thick description," and, relatedly, the interpretative nature of ethnographies as reflexive texts versus objective representations of the world.

Participant observation is the cornerstone of ethnography. Like traditional ethnography, online ethnography hinges on participant observation. Rather than going out into the field, online ethnography requires researchers to use the tools and technologies that help to create and support the worlds they study. While a traditional ethnography may study the world of surgery without learning to use a scalpel, an online ethnographer must learn to use at least some of the tools used by participants in a virtual community simply to gain access to the field site. In my case, this means I needed to learn how to create an account for Wikipedia and how to engage with other editors using talk pages, Internet Relay Chat (IRC), and Wikipedia email. To observe different kinds of activities and interactions, I also needed to learn how to create a user page, how to edit Wikipedia using mark-up, how to upload images to Commons, how to apply templates, how to host an edit-a-thon, how to apply for a grant and respond to questions from the community, how to add articles to my watchlist, how to subscribe to bots, how to apply categories, and how to revert vandalism. I also needed to spend time "hanging out" on Wikipedia, attending Wikimania, participating in mailing lists, and learning the cultural norms and paradoxical rules of the community. As Boellstorff and his colleagues (2012) write, "It is our responsibility [as online ethnographers] to get up to speed regarding the basics of everyday life in the virtual world we wish to study" (p. 73). During this time, it is also the online ethnographer's responsibility to take fieldnotes, capturing interactions and insights as they occur on and offline, which leads me to "thick description."

According to Lincoln and Guba (1985), *thick description* "must specify everything that a reader may need to know in order to understand the findings" (p. 125). Although the term was first introduced by

British philosopher Gilbert Ryle, Clifford Geertz (1973), an American anthropologist, is the scholar who popularized it, explaining that what an ethnographer does is write about "extremely small matters" so that they might understand human experience in context:

> So, there are three characteristics of ethnographic description: it is interpretative; what it is interpretative of is the flow of social discourse; and the interpreting involved consists in trying to rescue the "said" of such discourse from its perishing occasions and fix it in perusable terms… But there is, in addition, a fourth characteristic of such description, at least as I practice it: it is microscopic. (p. 318)

It is this microscopic attention that engenders "thick description," situating what is said and done in a particular time and place so that reader can understand not only the context but also the meaning of the discourse or actions. Because Wikipedia is such a distinctive culture, I have used "thick description" throughout, providing context for Wikipedia as a site of study in Chapter 3 and treating each object biography as an opportunity to practice microscopic attention.

Finally, the writing of this dissertation work is ethnographic in nature. This is a reflexive text that is as much about me as it is about women's health information on the English language Wikipedia. My feminist epistemology and understanding of the world have shaped my selection and analysis of data as well as my narrative voice. I do not intend for this study to be an objective representation of the world—first and foremost because I reject objectivity in social science. Below, I share more about my researcher stance and how I gained access to the community as well as how this dissertation work should be evaluated as an inductive and interpretative piece of qualitative scholarship.

Researcher stance

As a qualitative researcher, I recognize I play a critical role in shaping and interpreting data. As a feminist researcher, I realize I am enmeshed in webs of power relationships. I am a white, cisgender, heterosexual, able-bodied woman who is well-educated, speaks English fluently, resides in the Global North, has access to technological and information resources, and has the socio-economic privilege to devote time to academic research. (I share this positionality with many but not all of the participants in my study.) I am also a feminist. In fact, through the process of engaging with the topic of this study, I have become increasingly sensitized to issues of gender bias, sexism, harassment, systemic bias, epistemic injustice, and activism.

Relevant to the topical domain of women's health, I suffer from migraines and debilitating menstrual cramps, have used birth control, and have been at risk of cervical cancer due to a human papillomavirus (HPV) infection. I have accompanied friends to cosmetic (e.g., breast augmentations and reductions, facelifts) and obstetric and gynecological (e.g., pregnancy tests, sonograms, abortions) procedures. I am not a medical professional, and I have no formal medical training; I am relatively healthy and—apart from migraines—have never experienced any kind of chronic illness or condition. I have been treated as an out-patient, but I have never been hospitalized. I am privileged to have excellent health insurance and access to world-class health care through the University of Washington.

Becoming a Wikipedian

I have engaged in the Wikimedia communities as an active participant-observer for more than five years. During this time, I have become invested in both the virtual and physical worlds of Wikipedia. I have created and edited articles, uploaded images to Wikimedia Commons, co-hosted and participated in edit-a-thons, attended local chapter meetings, applied for and received a research grant from the Wikimedia Foundation (WMF), served on a grants committee for the WMF, written posts for the WMF's blog (Menking, 2014; Menking, 2015), subscribed and posted to mailing lists, been a member of private Facebook groups for women Wikipedians, become friends with former and current WMF employees, served on the advisory board of Whose Knowledge? (a nonprofit organization started by two former WMF employees), joined and participated in WikiProjects, and even briefly shared a house with a former Foundation employee. I am what Adler & Adler (1987) describe as an *active member-researcher*:

> With active membership, the researcher moves clearly away from the marginally involved role of the traditional participant observer and assumes a more central position in the setting. Researchers who adopt active membership roles do more than participate in the social activities of group members; they take part in the core activities of the group […]. In so doing, they generally assume functional, not solely research or social, roles in their settings. Active-member-researchers (AMRs), therefore, relate to members of the setting in a qualitatively different way […]. Instead of merely sharing the status of insiders, they interact as colleagues: coparticipants in a joint endeavor.

My progress from being a "newbie" to an active-member researcher was challenging. I was initially overwhelmed by Wikipedia, both the system and the culture. I felt as though I had arrived late to a dinner party at which I knew no one and everyone was speaking another language. However, I recently found myself explaining Wikipedia to another researcher in preparation for an edit-a-thon she was organizing, and I realized I had, perhaps without knowing it, become a Wikipedian. As Boellstorff and his colleagues (2012) write, "The 'newbie' experience is pivotal for ethnographers, and we should not sidestep the value we gain from watching ourselves go through that process" (p. 74).

Pulling back the curtain

Prior to 2013, I had a low opinion of Wikipedia. As a former high school English teacher, if I thought about Wikipedia at all, I thought of it as nothing more than an unreliable website. (I told students that if they cited it, they were guaranteed to earn zeros.) It was not until I worked as a Teaching Assistant (TA) for an undergraduate course about computer-supported cooperative work (CSCW) at the University of Washington that I realized there was much more to Wikipedia. The professor teaching the course used Wikipedia as a case study and, as I did the readings, attended lectures, facilitated labs, and graded student work, I was able to pull back the curtain to reveal not a single man in topcoat standing before a panel of instruments but rather a global community of individuals invisibly tied together by a few shared values, some seemingly paradoxical norms, and a complex and sprawling system.

In the midst of learning more about Wikipedia, I also learned about the gender gap. But the course readings that touched on the gender gap were unsatisfactory. They framed it as a "woman problem," and I was surprised to find that no one had talked to the women who edit Wikipedia about their experiences and perspectives. The professor of the course—who would later become my co-advisor—encouraged me to think more carefully about the gender gap, noting that most research up until that date had not asked (or answered) the more challenging questions about why the gap existed or whether it mattered. And that is how I fell down the proverbial rabbit hole, or, as Wikipedia describes it: *a metaphor for an entry into the unknown, the disorienting or the mentally deranging*.[29]

Falling down the rabbit hole

I decided to interview women Wikipedians to learn more about who they were, why they contributed, and what they thought about the gender gap. I began by creating a page on Meta, Wikimedia's main site. The goal of the page was to ask permission from the Wikimedia Foundation (WMF) Research Committee (RCom) to conduct research in and on Wikipedia. This was especially important as I planned to recruit participants via Wikipedia, using talk pages, IRC, and Wikipedia email. At the time, I did not realize the Research Committee was an informal group made up of a handful of Foundation employees—all of whom were white, cisgender men. I also did not realize they had yet to define their goals and processes. Some of this began to become clear as I replied to questions and comments on the discussion page. For example, a Foundation employee I knew only by his Wikipedia username asked me to post my survey questions and interview protocols. I was hesitant to do so because I did not want to prime any potential participants and because I wanted to retain the flexibility to adjust my data collection instruments as I collected data. I sent him an email outlining my concerns; at the time, I did not realize that taking a conversation "off-Wiki" was a *faux-pas,* but his email reply and posts to the discussion page made that clear. I became even more confused (and frustrated) when the same person posted the following comment:

> Without citing specific examples of the questions you intend to ask (that presumably have not been asked before), the larger research questions you intend to answer or citations to specific examples of previous work not asking/answering these questions, it's hard to see where you intend to make novel contributions. I'm also curious what you mean when you say "feminist research methods". Which methods occur in this category?

Why was he asking me to explicate "feminist research methods"? Was he asking on his own behalf or on behalf of the Research Committee? Did the Research Committee exist to vet my study for ethical concerns and potential impact on the community, or were they also serving as a kind of pre-peer review process assessing "novel contributions" before the study began? When another Foundation employee asked whether I would be considering survivorship bias, yet another Foundation employee replied:

> Since our process is largely undocumented, it's probably not self-evident to the researcher under review which questions represent "issues to be fixed" and which ones are simply "points to be discussed". Perhaps in future we can just lump them all under two different standard headers: "Review questions" and "Peer feedback" or something?

Indeed, nothing about the process was "self-evident" to me. After more discussion, there was a "straw poll," to answer, "Is this research project ready for RCom's approval?" My study was approved, but—more importantly—I had learned how to survive the fall and orient myself to this new world called Wikipedia.

Gaining access

A few months into my research project, a Ph.D. student from another university who was also researching Wikipedia contacted me. She had not been able to get approval from the WMF Research

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[29] See https://en.wikipedia.org/wiki/Rabbit_hole

Committee and had proceeded to recruit and interviewee Wikipedians without it. She was frustrated by the overall lack of response and chose to use a WMF mailing list devoted to women Wikipedians in Australia for recruitment. In her resulting publication, she notes:

> Initially, I sought support from Wikipedia itself to recruit participants. Wikimedia Foundation has a Research Committee […]. But, after a long and drawn-out process (as of this writing, it's been nearly a year and a half and I still have yet to receive any official word), I decided to try a different approach [...]. (Gruwell, 2016, p. 122)

In speaking with her, I realized I had gained access to the community more easily than she had because of my association with several well-respected Wikipedia researchers and Wikipedians—all of whom are white, cisgender men—and two of whom serve on my dissertation committee. Not only was I associated with these men socially and professionally, I also benefited from their expertise and advice as I navigated approval from the Research Committee and applied for and secured an Individual Engagement Grant (IEG) from the Wikimedia Foundation. But some of these relationships did not come without a cost.

Being a woman researching Wikipedia

Although this study is not explicitly about what it means to be a woman on Wikipedia or to be a woman researching Wikipedia, my gender has shaped my interactions with my analytic topic and impacted my engagement with the community. For example, my engagement in Wikipedia research was further complicated when another Ph.D. student, who initially encouraged me to research the gender gap, assumed I was sexually interested in him because I wore "low cut t-shirts and tight jeans" when we met for coffee. He explained that he could not date me, but he understood how I looked up to him as he was further along in his studies and had "a lot of knowledge about" and "connections" within the Wikipedia communities.[30] I would think about this experience a year later when I interviewed a woman Wikipedian via Skype. She told me she often felt uncomfortable at meet-ups and had experienced several unwanted sexual advances:

> *There was also a guy that I met at an event I spoke at in [city name], that I was invited to and paid to speak at. He had come from outside the city to watch and we ended up walking to the bus together to leave the city. When we said goodbye, I went to give him a friendly hug, and he straight up kissed me, barely missing my lips, and this was not like an art world, French goodbye, it was like he just decided he wanted to kiss me and did it. I just walked away and am ignoring his messages online now. Annoying. […] No, I haven't reported it. But my female Wikipedia friends and I gossip about such incidents often.*

Like this participant, I did not report the unwanted sexual advances I experienced in the community or the sexism that seemed to be par for the course. For example, the WMF employee who previously challenged me to explain "feminist research methods" on the discussion page of my request for approval from the Research Committee would, a few years later, accuse me via email of being on a "crusade about gender." A year after his email, he would co-author an article in which he leveraged feminist theory. At this point, I already felt marginalized and, besides, to whom would I report these incidents?

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[30] When I started my doctorate program in 2012, I created a Google document dedicated to writing about my experiences. I wrote about these interactions in that personal journal. The phrases in quotation marks are direct quotes.

Like many participants in this study and previous studies (Menking, Erickson & Pratt, 2019), I had learned that speaking out often resulted in more frustration, anxiety, and emotional labor.

Being a (critical) part of the movement

Two years ago, I was attending an event in Seattle when Alex[*], a long-time Wikimedian, greeted me with a hug. I had not seen him in person since Wikimania 2014 in London when we first met. "I'm so happy you're still a part of the movement," he said, and I finally felt like maybe I really was. As I stood next to him and his partner and we asked people to write down the kinds of information they thought were missing from Wikipedia and the internet, I reflected on the politics of free knowledge. As a feminist, I want Wikipedia to belong to the world. I want it to fulfill its promise of being "the encyclopedia anyone can edit." I believe in free speech, knowledge for everyone, and community sharing—on the surface, at least. I am and, even after this dissertation work is complete, will continue to be a part of the movement. But it is most likely I will always be a critical member, echoing the concerns of Ford and Wajcman (2017) from the margins:

> Wikipedia is a knowledge institution governed by issues of power. Although presented as objective knowledge, the encyclopedia's frame necessarily limits what (and consequently who) can be included. […] Those who are able to master Wikipedia's technocratic system of representation, with an emphasis on facts and other modular pieces of verifiable information, emerge as power brokers within this environment. Those who fail to master this system, either because their knowledge of the world does not fit with what Wikipedia recognizes as knowledge or because negative social interactions on the platform have led to their leaving it, will remain on Wikipedia's edges, unable to contribute and have their knowledge represented.

Partly due to my positionality and privilege, I have mastered the system enough to study and participate in it. I have also found a community around the edges—a community of people like Alex and his partner who are also working to make Wikipedia more inclusive.

Interviews

Sampling and recruitment

Between June 2016 and January 2018, I used purposive sampling—specifically *expert sampling*—to recruit potential participants for interviews (Etikan, Musa, & Alkassim, 2016). Because of the focus of this study, I was most interested in talking to editors who were either explicit, active members of WikiProject Women's Health and/or had made significant contributions to one of the articles I selected as a candidate for object biography. I recruited prospective participants through Wikipedia email (see Appendix C). I avoided using You've Got Mail (YGM) notifications on editor's talk pages because I did not want to compromise their confidentiality. I copied myself on all emails, using my University of Washington email address. In total, I contacted 26 editors; 17 replied and 14 consented to interviews. I provided all potential participants with electronic copies of a description of my study and consent form (see Appendix D).

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[*] I have used a pseudonym here to protect Alex's identity.

Data collection

I conducted semi-structured interviews in English via phone, Skype, or Google Hangouts. I audio-recorded interviews while taking handwritten notes. Interviews ranged in duration from 30 minutes to more than two hours. I interviewed one editor twice as he is very active in medical content creation/curation and is not only a WikiProject Women's Health member but has also contributed significant content to three of the articles identified for potential object biographies. I had previously interviewed three of the editors in past work about women and Wikipedia, and I had previously met four of the editors in person at either Wikimania or local edit-a-thons.

Data analysis

I transcribed all audio-recordings verbatim with the exception of one (Carolyn) because the audio-recording failed. (I took notes during and immediately following the interview and sent these to her for review). After transcribing the audio-recordings, I destroyed the recordings and imported all interview transcripts and notes into NVivo, a qualitative data analysis software tool, where I conducted *in vivo* coding (Manning, 2017). Because the interview data was collected iteratively and in tandem with other data (e.g., documents for analysis), I used open coding and memoing to identify emerging themes across data sources (e.g., Miles & Huberman, 1984; Strauss & Corbin, 1998). As I identified these themes, I modified my interview protocol (see Appendix E). I returned to the data and did another round of open coding across transcripts, notes, and documents. Then, I conducted axial coding.

Demographics

In total, I interviewed 14 Wikipedians (seven women; seven men). They ranged in age from mid 20s to early 70s and resided primarily in North America with the exception of two participants who resided in Australia and Sweden. Overall, they represented a significant upward skew in education with seven participants having had some degree of formal medical training and 10 having at least one advanced degree. Among participants, the only ones who reported having children at home were men who also reported having partners. The women I interviewed either did not have children or their children were adults who no longer lived at home. On average, they have 10.9 years of editing experience on the English language Wikipedia in addition to editing other languages and working on related projects. However, five participants reported they were no longer active editors. See Table 1.4.

*Table 1.4. Participant demographics with assigned pseudonyms, gender, indication of formal medical training at the postgraduate level, and the number of years editing the English language Wikipedia at the time of interview. The date of interview is indicated in the last column. I interviewed Henry twice, which is why two dates are listed. * Editors who were interviewed about specific articles.*

Pseudonym	Gender	Formal medical training?	Years	Date
Carolyn *	Woman	N	11	07/31/2017
Eileen	Woman	N	11	01/12/2018
Henry *	Man	Y	11	07/18/2016 12/11/2017
John *	Man	N	11	08/03/2017
Josh *	Man	N	11	11/07/2017

Karsten *	Man	N	15	11/14/2017
Kate	Woman	Y	2	06/30/2016
Matthew	Man	N	12	07/12/2016
Navi	Woman	Y	8	08/05/2016
Sara	Woman	Y	11	07/02/2016
Shanna *	Woman	N	13	08/01/2017
Simon *	Man	Y	12	12/28/2017
Whitney	Woman	Y	13	07/08/2016
William	Man	Y	12	09/15/2016

Document Analysis

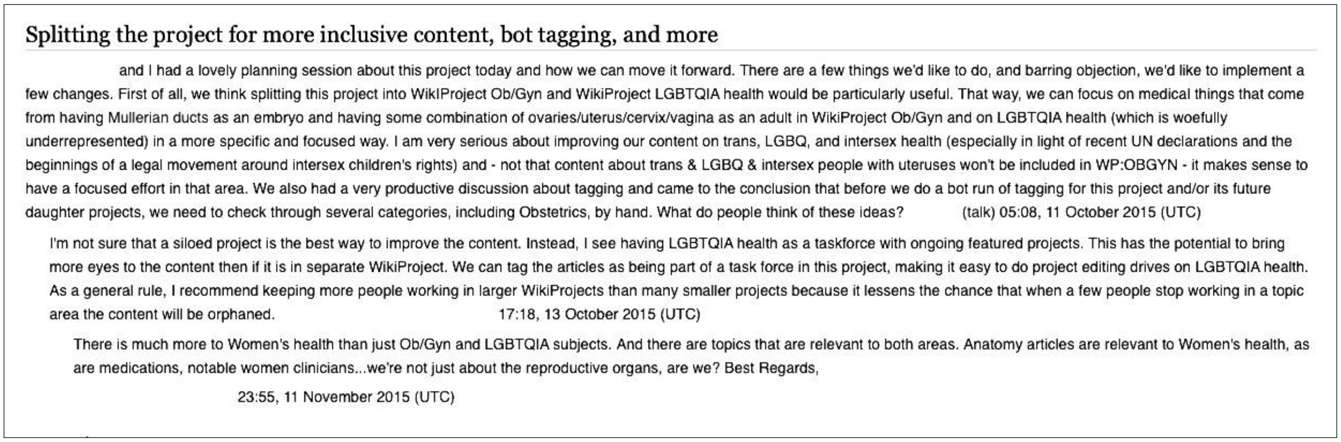
Document analysis is a systematic procedure for reviewing or evaluating documents—both printed and electronic (computer-based and Internet-transmitted) material. Like other analytical methods in qualitative research, document analysis requires that data be examined and interpreted to elicit meaning, gain understanding, and develop empirical knowledge (e.g., Corbin & Strauss, 2008; Bowen, 2009). Document analysis is often used in combination with other qualitative research methods as a means of triangulation (Bowen, 2009). In this study, I used document analysis in Chapter 5 to interrogate Wikipedia project pages, revision histories, and talk pages as supplementary data to triangulate interview data and to understand better the context of women's health information on the English language Wikipedia.

Data collection

To begin, I manually reviewed and took screenshots of every page belonging to WikiProject Women's Health, including talk pages and revision histories. As I conducted interviews, I broadened my review of documents based on feedback from participants and references they made during interviews. In total, I analyzed 16 documents and reviewed dozens more. All of these documents are publicly available.

Data analysis

After I collected the 16 documents (or pages) as screenshots, I imported them into NVivo where I used open coding. At the same time, I wrote memos to identify emerging themes across the documents and interview data. I was particularly interested in passages in which Wikipedia editors discussed how to scope WikiProject Women's Health (see Figure 1.4), including excerpts from WikiProject Council proposal pages and Category pages (e.g., Category: Women's health) as well as the Administrator's Noticeboard, where editors discussed banning an editor from editing women's health-related content.



Splitting the project for more inclusive content, bot tagging, and more

[redacted] and I had a lovely planning session about this project today and how we can move it forward. There are a few things we'd like to do, and barring objection, we'd like to implement a few changes. First of all, we think splitting this project into WikiProject Ob/Gyn and WikiProject LGBTQIA health would be particularly useful. That way, we can focus on medical things that come from having Mullerian ducts as an embryo and having some combination of ovaries/uterus/cervix/vagina as an adult in WikiProject Ob/Gyn and on LGBTQIA health (which is woefully underrepresented) in a more specific and focused way. I am very serious about improving our content on trans, LGBQ, and intersex health (especially in light of recent UN declarations and the beginnings of a legal movement around intersex children's rights) and - not that content about trans & LGBQ & intersex people with uteruses won't be included in WP:OBGYN - it makes sense to have a focused effort in that area. We also had a very productive discussion about tagging and came to the conclusion that before we do a bot run of tagging for this project and/or its future daughter projects, we need to check through several categories, including Obstetrics, by hand. What do people think of these ideas? [redacted] (talk) 05:08, 11 October 2015 (UTC)

I'm not sure that a siloed project is the best way to improve the content. Instead, I see having LGBTQIA health as a taskforce with ongoing featured projects. This has the potential to bring more eyes to the content then if it is in separate WikiProject. We can tag the articles as being part of a task force in this project, making it easy to do project editing drives on LGBTQIA health. As a general rule, I recommend keeping more people working in larger WikiProjects than many smaller projects because it lessens the chance that when a few people stop working in a topic area the content will be orphaned. [redacted] 17:18, 13 October 2015 (UTC)

There is much more to Women's health than just Ob/Gyn and LGBTQIA subjects. And there are topics that are relevant to both areas. Anatomy articles are relevant to Women's health, as are medications, notable women clinicians...we're not just about the reproductive organs, are we? Best Regards,

[redacted] 23:55, 11 November 2015 (UTC)

Figure 1.4. A screenshot of one section from the WikiProject Women's Health talk page archive with Wikipedia editors' usernames redacted. This section contains an original post with two comments. During my analysis, I made several annotations here, including "defining women's health," "medical things," "LGBTQIA health," "legal movement," "bots," "OB-GYN," "more eyes," "reduced to reproductive organs," and "women's health as boundary object." I then compared these annotations to the codes and categories emerging in the interview data.

Object Biography

> Biographies of things make salient what might otherwise remain obscure.
>
> Igor Kopytoff, 1986

Annie Carey, a science writer for children, wrote some of the earliest object biographies in her 1870 publication *Autobiographies of a lump of coal, a grain of salt, a drop of water, a bit of old iron, a piece of flint*. As she wrote in the preface, Carey sought to help children discover "the truth of things" [*quoted in* Briggs, 1988, p. 297]. And though Carey was the first to write an object biography, Igor Kopytoff (1986) is most often credited with the idea. His proposition in "The Cultural Biography of Objects" is primarily concerned with commoditization and, thus, takes up questions of how any particular object becomes a commodity or a gift. Notably, Kopytoff's concept of object biography differs from the life-history approach used in archeology in that the latter focuses on long-term changes from a systems perspective, often disregarding daily interactions between and objects and people (Humphries & Smith, 2014). The goal of an object biography, then, is to understand the life-history of an object—how it is a culturally constructed artifact with a social life (or lives), moving through production, consumption, exchange, disrepair, maintenance, and discontinued use or death (Gosden & Marshall, 1999). Put simply, an object biography tells the story of an object's life as a biography tells the story of an individual's life. And just as an individual's biography may focus on a particular narrative—"psychological, professional, political, familial, economic and so forth—[selecting] some aspects of the life history and [discarding] others" (Kopytoff, 1986, p. 68), so too may an object biography, emphasizing some aspects of an object's life over other aspects.

Anthropologists have used object biography to examine looped string bags in Central New Guinea to understand gender relationships (MacKenzie, 1991), public practices, poetic speech, and valued objects to question representation broadly and power and agency specifically in Indonesia (Keane, 1997), and a range of objects from kola nuts, cotton clothes, and palm oil to understand violence in Sierra Leone (Ferme, 2001). Researchers outside of anthropology have used object biography too. For example, in their 2014 study of a 914 Xerox copier, organizational scholars Humphries & Smith (2014) used object biography to interrogate changing organizational relationships over time and, in her LIS dissertation work, Kathy Carbone used object biography to understand how local artists engaged with police surveillance records in Portland, Oregon (2017).

But why use an object biography for a digital object? As Lehdonvirta (2010) notes, non-material culture can reproduce inequality, and exclusion and digital spaces are not free from offline identities, institutions, and structural biases. Moreover, "virtual space is not an open frontier" (Lehdonvirta, 2010, p. 885); it is shaped by the technical infrastructures that frame its borders and determine how (and sometimes when) inhabitants can interact with one another and the system itself. Similarly, in his investigations of the materialities of information, Paul Dourish (2017) writes:

> Representational systems are material in their manifestations; they occupy space, they constrain human action, they are coupled to practice, and they condition technological configurations. […] Digital representations are formal; their forms are what matter, and forms are material in the ways in which they can and cannot be used. (p. 203)

Thus, digital objects—like Wikipedia articles—are not only representations of material objects, they are also material in how they impact the ways in which people can interact with them. In a recent paper, STS scholars Hyysalo, Pollock & Williams (2018) argue "biographies of artifacts and practices" (BOAP) address some methodological shortfalls in STS while providing "the means to explore, rather than take for granted, the different actors and factors in the course of the social shaping of technology" (p. 15). In this dissertation work, I adapt object biography to interrogate specific Wikipedia articles, which to my knowledge has yet to be done.

Sampling

To select articles for object biographies, I used Trost's (1986) approach to statistically non-representative stratified sampling. Trost recommends listing independent variables relevant to the purpose of the study which can then be dichotomized or trichotomized (p. 55). I considered three variables when selecting object biography candidates: (1) whether an article discussed a condition, illness, or disease pertaining to sexual and reproductive health or non-reproductive health, (2) the prevalence rate of said condition, illness, or disease, and (3) the associated stigma.

For the purpose of this selection process, prevalence rate was determined by the proportion of a population that has a particular a condition, illness, disease, injury, other health condition, or attribute at a specified point in time or during a specified period.[31] *Rare* diseases in the United States are those that affect 200,000 individuals or fewer. The threshold for a *common* disease is less well-defined, but it is generally considered to be greater than the threshold for a rare disease.

Stigma is less well-defined than prevalence, but for the purposes of this study, I referred to the "stigma scale" (King et al., 2007) which considers discrimination and disclosure in the context of mental illness. Because all potential topics are related to women's health and women are a minority group, all topics carry some degree of stigma depending upon a woman's race, age, socioeconomic class, abilities, sexual preferences, or religious upbringing. For example, stigma scales have been adapted to measure sexual

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[31] See https://www.cdc.gov/ophss/csels/dsepd/ss1978/lesson3/section2.html

stigma among lesbian, bisexual, and queer women (Logie & Earnshaw, 2015), and research shows that women who have had abortions face stigma in many contexts (see special issue of Women & Health, vol 54, no 7). For the purposes of this study, I draw on Deacon (2006) and consider *high* stigma to be those illnesses or conditions perceived as preventable and/or controllable and as being caused by "immoral" behaviors, resulting in the patient being blamed for her illness or condition (e.g., cervical cancer is caused by HPV, which is an STI, and women are still held to a double-standard regarding sexual activity). *Low* stigma includes illnesses or conditions not perceived as being preventable and/or controllable, and for which the patient is unlikely to be blamed (e.g., the risk factors for testicular cancer include cryptorchidism and a family of history of testicular cancer; a patient has no control over either).

After I decided on these variables, I then considered (1) whether the topic was represented by an article on the English language Wikipedia and (2) if so, that article's quality. The former was operationalized by searching for the article using Wikipedia's native search feature. The latter was operationalized according to Wikipedia's internal metrics (e.g., Featured Article, Good Article) from which I created three categories: low, mid, and high. *Low* consists of Stub and Start class articles. *Mid* consists of C and B class articles. *High* consists of Good Articles and Featured Articles.[32] As Shafee and his colleagues (2017) write of medical and health related content on Wikipedia:

> Wikipedia articles are rated by importance and quality by the communities of editors […]. Top-importance articles include conditions of global significance, such as tuberculosis and pneumonia. High-importance includes common diseases and treatments. Mid-importance encompasses conditions, tests, drugs, anatomy and symptoms. The remaining low-importance articles include niche or peripheral medical topics such as laws, physicians and rare conditions. Articles are similarly rated for quality on a scale 'Stub', 'Start', 'C', 'B', 'Good Article' (GA) and 'Featured Article' (FA). The latter two categories are only assigned after an internal peer review process. GAs comprise 0.7% of medical articles and require a single peer reviewer. FAs comprise 0.2% of medical articles and have to pass more stringent criteria and often have 5–10 reviewers.

This sampling method allowed me to narrow my focus from thousands of articles to 19 (see Table 2.4). To further narrow my focus, I collected data about each of the 19 articles and performed preliminary analysis before selecting three about which to write life-histories.

Another approach to selecting an object is reflected in Derks' (2015) study of the beehive coal briquette in Vietnam; while she relied upon extensive fieldwork, including more than 100 interviews and 400 household surveys, collected over two years to craft her object biography, her initial interest in the beehive coal briquette was sparked when an elderly lady tried to stop her from taking a picture of briquette stoves in an alley. Thus, attention to signals of how a community thinks about or responds to an artifact may guide selection. As Hoskins, writes:

> […] various experiments [in object biography] have taken two dominant forms: (1) those 'object biographies' which begin with ethnographic research, and which thus try to render a narrative of how certain objects are perceived by the persons that they are linked to, and (2) efforts to

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[32] I used the same metrics used by WikiProject Women's Health. I did not use ORES, a web service and API that provides machine learning and is maintained by the Scoring Platform team, because it was not available when I began to collect article data for object biographies.

> ‘interrogate objects themselves’ which begin with historical or archaeological research, and try to make mute objects ‘speak’. (p.)

In short, selecting an object is dependent upon familiarity with the context or community in which it was created or currently exists. In addition to the interviews I conducted, my five years of ethnographic study as an *active member-researcher* (Adler & Adler, 1987) in the Wikimedia communities helped to shape my selection. This is what lead me to select *Women’s health* though it did not appear in the first sample (see Table 2.4).

Table 0.1.4. Potential article candidates for object biography selected using Trost’s sampling method (1986). As Trost notes, some cells may be logically or empirically empty (p. 55). For example, when I collected my data, I could not find a B or C class article about a reproductive and/or sexual health issue that was both rare and relatively low stigma.

Reproductive & Sexual Health												
Stigma	Low						High					
Prevalence	Rare			Common			Rare			Common		
Quality	Low	Mid	High	Low	Mid	High	Low	Mid	High	Low	Mid	High
Article	*Acute fatty liver of pregnancy*		*Coffin birth*	*Atrophic vaginitis*	*Menstruation*	*Birth control*	*Vaginal cancer*	*Endometriosis*	*Abortion–breast cancer hypothesis*	*Abortifacient*	*Human papillomavirus infection*	*HIV/AIDS*
Non-Reproductive Health												
Stigma	Low						High					
Prevalence	Rare			Common			Rare			Common		
Quality	Low	Mid	High	Low	Mid	High	Low	Mid	High	Low	Mid	High
Article		*Turner syndrome*		*Thyroid disease in women*	*Breast cancer*	*Migraine*	*Morgellons*	*Eating disorder*			*Violence against women*	*Major depressive disorder*

Data collection

Depending upon the class of object—physical, digital, or hybrid—data collection may involve scraping websites, taking photographs, gathering various documents (e.g., diaries, notebooks, records, technical documentation, policy manuals), observing interactions, conducting interviews and surveys, creating prototypes or facsimiles, or extracting data from the object itself. For example, in Pfaff’s (2010) 18 month study of a specific mobile phone as an object of Swahili mobility and trading practices, she describes how she followed the phone’s “career”—taking field notes, talking to people who owned or borrowed or used the phone, and even calling the phone herself—to ask “what it embodies, what it does and what it becomes” (p. 346). In this way, an object biography takes up the grounded theory dictum *all is data* (e.g., Glaser & Strauss, 1967; Ralph, Birks & Chapman, 2014).

For each article, I collected article revision histories, talk page discussions, and trace data. To do this, I used a Python script to scrape Wikipedia, collecting all revisions and logs for each article to create two CSV files for each article: revision data and log data. I also manually inspected each revision for each article and took screenshots of versions that evidenced significant content change (i.e., the inclusion of a new paragraph), introduced new references or resources, or images. I read all talk page discussions, took screenshots of page information data, and downloaded page view data. I also added each article page discussed in Chapter 6 to my watchlist, a page that allows users who are logged in to receive notifications when changes are made to selected article pages and their associated talk pages.

Data analysis

All article data was analyzed in a non-linear and iterative fashion. For example, I coded the log and revision data I downloaded into CSV files, noting different kinds of edits, including acts of vandalism (VAN) and subsequent reversions (REVERT), applications of categories (CAT) and tags (TAG), and content creation (CC), as I manually inspected revision histories on Wikipedia. During this time, I also conducted axial coding of a subset of related interview data and wrote memos to identify emerging themes.

Evaluating Qualitative Research

As with all qualitative or naturalistic work, this study should be evaluated based on its *trustworthiness*, which allows the researcher to make reasonable claims regarding methodological soundness (Lincoln & Guba, 1985). A researcher establishes trustworthiness “by the use of techniques that provide truth value through credibility, applicability through transferability, consistency through dependability, and neutrality through confirmability” (Erlandson et al., 1993). Credibility and transferability can also be understood in terms of *validity,* and dependability can also be understood in terms of *reliability*. Given the feminist lens I use here, I reject notions of neutrality in favor of *holistic reflexivity* (Hesse-Biber & Piatelli, 2007), which I say more about below.

To ensure *internal validity*, I have relied on prolonged engagement (e.g., five years of ethnographic research), persistent observation (e.g., five years of being an active-member researcher), triangulation (e.g., fieldnotes, interview transcripts and notes, document analysis, trace data), member checking, and reflexive journaling in addition to memoing. To ensure *external validity*, as noted above, I relied on both “thick description” and purposive sampling.

To ensure *reliability*, I relied on reflexive journaling and a comprehensive audit trail. The former took place in Google documents and NVivo, while the latter spanned Google documents, Word documents, handwritten notes, and NVivo files. Lincoln & Guba (1985) outline six categories of audit trail materials: raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, materials relating to intentions and dispositions, and information relevant to any instrument development (pp. 319-320). For example, while I destroyed audio recordings of interviews, I maintained all interview transcripts and notes in both Word documents and NVivo files (i.e., raw data). In NVivo, I have also maintained data reduction and analysis products in the form of nodes, cases, and notes. Throughout this dissertation work, I share samples of data reconstruction and synthesis products (see Table 2.5), excerpts from process notes (see Chapter 5), and examples of instruments (see Appendices).

Holistic reflexivity “exposes the exercise of power throughout the entire research process” (Hesse-Biber & Piatelli, 2007, p. 495) by asking what we can know and how we know it with attention to interlocking identities such as race, gender, and class as well as insider/outsider positionalities including the researcher’s own. Although holistic reflexivity aligns with the kinds of audit trails other researchers (e.g., Lincoln & Guba, 1985; Erlandson et al., 1993) recommend using to establish confirmability, it also requires that a researcher practices *reflexivity sampling*—checking in with one’s self throughout the research process to ask about one’s biases, social locations and identities, relationships with participants, and any emotional or intellectual reactions to the data. During the past seven years, I have kept a personal journal in which I have reflected on my experiences in the doctoral program, including my positionality and privilege and relationships with Wikimedians. I have also written short stories, including the story about Sosi from which I shared an excerpt at the beginning of this dissertation work, in which I have creatively interrogated some of the themes emerging in my data. Both of these activities have prompted me to continuously reflect upon who I am, what I can know, and how I know what I do as a researcher.

Summary

In summary, the methodology I have chosen for this dissertation work reflects my dedication to feminist epistemology, context, and complexity. It is bound up in five years of ethnographic research in and about the English language Wikipedia and is my attempt to tease apart complicated relationships between gender, evidence, expertise, medicalization, and knowledge production in sociotechnical systems like Wikipedia. Although I have been rigorous in my data collection and analysis, I have also taken risks, adapting a method from anthropology and material culture to study (primarily) digital information objects. Furthermore, because this dissertation work has not been through a formal peer review process and, thus, has not been sharpened by other scholars’ insights, it is rudimentary in many ways. It does, however, provide an entry point for future inquiry and document the questions I have tried to love as patiently as possible.

Chapter 5: Creating Women's Health Content on Wikipedia

Introduction

When Donna Strickland was awarded the Nobel Prize in 2018, Wikipedia editors rushed to create an article about her. The press picked up on this flurry of activity and—once they learned that a previous draft of the *Donna Strickland* article had been deleted due to notability concerns—they further criticized Wikipedia (e.g., Koren, 2018). Katherine Maher, the Executive Director of the Wikimedia Foundation, was quick to respond to this criticism. In her October 18, 2018 Op-Ed for the *Los Angeles Times*, she writes:

> Technology can help identify such problems [as bias]. Wikipedia articles about health get close attention from our community of medical editors, but for years, some articles on critical women's health issues, such as breastfeeding, languished under a "low importance" categorization. An algorithm identified this mistake. (Maher, 2018)

What Maher does not mention is that Wikipedia's "community of medical editors" is relatively small (Shafee et al., 2017), and, perhaps as a consequence, *many* articles on critical women's health issues were overlooked for more than a decade—and many continue not to "get close attention" today.[33] In fact, as recently as May 2015, an experienced Wikipedian and Wikimedia Foundation employee proposed that a new WikiProject dedicated to women's health be created to the improve women's health information on the site:

> Women's health articles need a lot of improvement. Many of them are outdated or overly jargony [*sic*]. They tend to be written for medical professionals and researchers and often have little or no practical information for women interested in their own health. This project would compliment [*sic*] the WikiProjects listed above by improving and expanding these articles, including adding information of practical value to women, and addressing social and political topics related to women's health. It would also strive to keep these articles up to date with the latest medical and scientific research […]. As a stand-alone project it would provide a prominent entry point for women editors interested in health issues, and hopefully contribute towards addressing Wikipedia's Gender gap.

In 2016, I set out to study the resulting project: WikiProject Women's Health. I wanted to learn more about the project, about women's health information on the English language Wikipedia, and about the editors who create, edit, and curate it. Going into the study, I had a few informal hypotheses based on prior studies about Wikipedia's participatory and content gaps (e.g., Lam et al., 2011; Graells-Garrido, Lalmas & Menczer, 2015; Wagner et al., 2015; Wagner et al., 2016) and five years of ethnographic research about Wikipedia's participatory gender gap (Menking & Erikson, 2015; Menking, Zachry & McDonald, 2017; Menking, Erickson & Pratt, 2019). Like the Wikipedian who initially proposed WikiProject Women's Health, I thought the participatory gender gap might be a factor in shaping women's health information on Wikipedia.

Because WikiProject Women's Health was new at the time and because women's health on Wikipedia is understudied in general, I framed my initial study as a preliminary investigation, asking: *Who started WikiProject Women's Health? Why? How do editors find out about the project? Why do they join? What*

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[33] Furthermore, as I discuss in Chapters 6-8, tools and technologies such as algorithms and bots are created by humans and, therefore, can perpetuate rather than mitigate biases, often in unintended ways.

motivates them to contribute? How do they envision their audience? What are editors' concerns about women's health information on Wikipedia? What kinds of information do they think is missing?

To answer these questions, I conducted semi-structured interviews with eight of the 11explicit WikiProject Women's Health members at the time.[34] As I prepared for and conducted these interviews, I read through the project proposal cited above, project pages (including talk pages), and dozens of articles associated with Wikiproject Women's Health, eventually performing document analysis on a selection of pages (*n*=16).

In this chapter, I present findings from these interviews and the related document analysis, answering my first set of research questions. These findings not only shaped my work with object biographies in Chapters 6 and 7, they also complicated assumptions (mine and others) about the relationships between the participatory gender gap and content gaps assumed to be gendered. Finally, they surfaced questions about expertise and knowledge production in user-generated content systems like Wikipedia, particularly when the content falls within a contested topical domain like women's health.

Background

I chose to study women's health information on the English language Wikipedia for several reasons. First, studies suggest women are more likely to seek health information online for themselves and on the behalf of others (e.g., Bernhardt & Felter, 2004; Percheski & Hargittai, 2011) and that they often use Wikipedia—one of the most powerful online information sources today—to do this (e.g., Buhi, Daley, Fuhrmann & Smith, 2009; Laurent & Vickers, 2009). Second, though WikiProject Medicine was established in 2004, WikiProject Women's Health was not established until 2015; I was curious as to why it took so long to establish the latter project and if the participatory gender gap played a role in this lag. Third, women's health information is a fraught topical area. Historically, women have been essentialized as reproducers (e.g., Inhorn, 2006; Neyer, & Bernardi 2011), have had their reports of pain and health concerns repeatedly dismissed (e.g., Ballard, Lowton & Wright, 2006; Dusenbery, 2018), and have been subject to discrimination and abuse at the hands of medical practitioners (e.g., Halas, 1979; Clarke, 1983; Krieger, Rowley, Herman, Avery, & Phillips, 1993). Women's health has always been an area in which "expertise" is debated; do medical practitioners know more about women's bodies than they do themselves? Moreover, women's health information spans conceptualizations of both gender and sex[35] (see Doyal, 2001) as well as a range of disciplines, public policies, and institutions: consider the topic of abortion. (See Chapter 2 for a more thorough discussion of women's health in general and women's health information online.) Finally, women's health information on Wikipedia has been understudied, and yet it is a topical area in which—if there is any relationship between the participatory gender gap and content gaps—one might expect to see some evidence. In the sections below, I provide a general overview of WikiProjects, including WikiProject Women's Health and WikiProject Medicine.

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[34] Explicit members are those who have signed up to the project.

[35] Sex and gender are organizing concepts. By this, I mean that, as a society, we use sex and gender as categories to organize all kinds of things—people, occupations, public bathrooms, items of clothing, and retail products. Some scholars argue that both sex and gender are socially constructed (Fausto-Sterling, 1993; Hubbard, 1990; Kessler, 1998; Dreger, 199; Davis & Preves, 2017); however, the prevailing consensus is that sex is primarily biologically based while gender is primarily socially constructed (Garbacik, 2013). Sex—the biological state of being male, female, or intersex—is historically understood as mostly binary in Western societies, though these views are rapidly changing. Gender—a collection of "behaviors, activities, roles, and actions that are socially attributed to boys, girls, men, women, and transgender people in a given society" (Garbacik, 2013, p. 7)—is, arguably, a fluid continuum of identity creation, performance, and re-creation.

For more information about Wikipedia as a site of study and, relatedly, about WikiProjects, please see Chapter 3.

WikiProjects

A WikiProject is a group of Wikipedians who work together either to accomplish specific editing tasks (i.e., copyediting, assessing the quality of articles) or to create, edit, and maintain content related to a particular topic (e.g., mathematics, video games, women scientists). The English language Wikipedia currently has over 2,000 such projects.

WikiProject Women's Health

WikiProject Women's Health (hereafter WP WH) was started in 2015, approximately 14 years after the English language Wikipedia was founded. At the time, 1,914 projects already existed; the first ten are listed by date created below (see Table 1.5). Forty projects total were created in 2015, including University of Oregon's Weaving Women into Wikipedia, Women in Technology, and Women in Red. According to the WP WH project page, the project focuses on "articles related to women's health, including related social and political issues." WikiProject Health and fitness, which could potentially overlap WP WH, was created nine years prior in 2006 and, according to its project page, is devoted to improving "health coverage and the organization of the subjects of health and fitness on Wikipedia." As of May 2019, WP WH consisted of 18 explicit, active members and 14 explicit, inactive members[36], including me. In comparison, as of May 2019, WikiProject Medicine consisted of 94 explicit, active members and more than 100 explicit, inactive members. To date and to my best knowledge, WP WH has not yet been studied.

Table 1.5. The first ten WikiProjects with current status and creation date as per May 1, 2019 via https://bambots.brucemyers.com/drb/WikiProjectList.html.

Project	**Status**	**Created**
WikiProject Sports	Active	09/26/2001
WikiProject Sports listing	Defunct	09/26/2001
WikiProject Sports team listing	Defunct	10/01/2001
WikiProject Days of the year	Active	10/15/2001
WikiProject History	Semi-active	10/22/2001
WikiProject Olympics	Uncategorized	03/01/2002
WikiProject Elements	Uncategorized	04/27/2002
WikiProject Biography	Active	06/19/2002
WikiProject Countries	Active	06/19/2002
WikiProject Tree of Life	Active	06/22/2002

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[36] Inactive members are those who have signed up but who have not edited within a month.

WikiProject Medicine

In contrast to WP WH, WikiProject Medicine (hereafter WP Medicine) was started in 2004, only three years after the English language Wikipedia was founded. According to WP Medicine's project page, the project is a place to "discuss, collaborate, and debate anything and everything relating to medicine and health on Wikipedia" (WikiProject Medicine, n.d.). Since its creation, WP Medicine has partnered with Cochrane, Cancer Research UK, and various medical schools, creating more than 40,000 articles and enlisting more than 90 active project members at any given time. Unlike WP WH, WP Medicine has received both media and scholarly attention (see Chapter 2).

Methods

I begin my methods section by addressing my relationship to the analytic topics: Wikipedia and women's health. I have engaged in five years of ethnographic study (late 2013-2019) as an *active member-researcher* (Adler & Adler, 1987) in the Wikimedia communities. I am a white, cisgender, heterosexual, able-bodied woman who is well-educated, speaks English fluently, resides in the Global North, has access to technological and information resources, and has the socio-economic privilege to devote time to academic research.

Relevant to the topical domain of women's health, I suffer from migraines and debilitating menstrual cramps, have used birth control, and have been at risk of cervical cancer due to a human papillomavirus (HPV) infection. I have accompanied friends to cosmetic (e.g., breast augmentations and reductions, facelifts) and obstetric and gynecological (e.g., pregnancy tests, sonograms, abortions) procedures. I am not a medical professional, and I have no formal medical training; I am relatively healthy and—apart from migraines—have never experienced any kind of chronic illness or condition. I have been treated as an out-patient, but I have never been hospitalized. I am privileged to have excellent health insurance and access to world-class health care at the University of Washington.

To read more about my positionality and researcher stance, please see Chapter 4.

Ethical considerations

I obtained Institutional Review Board (IRB) approval from the University of Washington before recruiting interviewees for this study. I provided all interviewees with study information and asked they (1) acknowledge they were 18 years of age or older and (2) provide either verbal or written consent. I offered interviewees compensation in the form of Amazon gift cards ($25 per physical card) funded by the University of Washington Information School's doctoral dissertation grant. For additional information about the ethical considerations of this study, please see Chapter 4.

Interviews

Timeline

To provide context for data collection and analysis as well as significant project and participant-related events, I have created the timeline below.

2015	+	*WikiProject Women's Health proposed via WikiProject Council pages*
	+	*WikiProject Women's Health is established*
	+	*WikiProject Women's Health adopts WikiProject X*
2016	+	*Conversation on WikiProject Women's Health discussion page begins to dwindle*
	o	Interviews with Henry, Kate, Navi, Whitney, Matthew, Sara, and William
	o	Document review
	o	Open-coding of interview transcripts begins
2017	o	Follow-up interview with Henry
	o	Document review and collection
	o	Continued analysis of interview transcripts
2018	o	Interview with Eileen
	+	*Editor X is topic-banned from editing sexuality, anatomy, and health articles*
	o	Document analysis
	o	Continued analysis of interview transcripts
	o	Joined WikiProject Women's Health
2019	o	Writing this chapter

Figure 1.5. Timeline of data collection and analysis with significant WikiProject Women's Health events.

Recruitment and sampling

To recruit interview participants, I reviewed the list of explicit WP WH project members provided on the project page and then reached out to all 11 members via Wikipedia's email (see Appendix C). I chose not to use the You've Got Mail (YGM) template on user talk pages because I did not want to draw attention to potential interviewees' participation given how small the editing community is. I used purposive sampling because I wanted to speak to people who were actively involved in WP WH as explicit project members.

Data collection

I conducted eight semi-structured interviews in English via telephony applications (e.g., Skype and Google Hangouts) and phone. I audio-recorded the interviews and took handwritten notes. Often during the interviews, the participants and I would share screens or take time to search for something on Wikipedia independently; I documented these moments in my notes. Interviews ranged in duration from 30 minutes to more than two hours. I had previously interviewed three of the editors in past work about Wikipedia's gender gap (Menking & Erickson, 2015; Menking, Erickson & Pratt, 2019), and I had previously met four of the editors in person at Wikimania (the annual conference for the Wikimedia communities) and/or at local edit-a-thons and meetups.

Data analysis

I transcribed all audio-recordings verbatim and then destroyed the audio-recordings. After transcription, I imported all interview transcripts and interview notes into NVivo, a qualitative data analysis software tool, where I conducted *in vivo* coding (Manning, 2017). Because the interview data was collected iteratively and in tandem with other data (e.g., documents for analysis), I used open coding and memoing to identify emerging themes across data sources (e.g., Miles & Huberman, 1984; Strauss & Corbin, 1998). As I identified these themes, I modified the interview protocol (see Appendix E). I then conducted axial coding. In total, 10 categories emerged in the analysis of the interview data (see Table 2.5).

Table 2.5. The 10 categories that emerged in the interview data with their corresponding codes and concepts and example excerpts.

Category	Associated codes/concepts	Example
Being an editor	All codes related to the experiences of being an editor on Wikipedia (e.g., motivations to contribute, belief in the movement, approaches to editing)	*I believe—you know, I believe what we're doing matters. So, all the bullshit we have to deal with and all the nastiness—you know, I'm here because I believe the people of the world need us. I'm not here to become friends with [name]. I'm here to do what needs to be done. I'm here to do what's right.*
Knowledge production	All codes related to how knowledge is produced and/or should be produced on Wikipedia, including criticisms of other editors' presumed epistemologies (e.g., evidence, expertise, medicalization)	*I'm very exclusive. I try to restrict myself to the kind of knowledge that only has scientific basis. So, I don't care whether it's Western or it comes from Indigenous medicine or whatever be the sources, it has to have some scientific basis to be able to appear on an article about women's health or Wikipedia in general.*
Content gaps	All codes related to content gaps (e.g., neglected articles, lack of images, impact of stigma on content, references to specific articles)	*It's true we have too few images related to medicine in general, and I think that applies to women's health as well. There's a shortage of images, and I'm aware of that part, and that was why I partnered with my medical school to get quality images from there and put them on Wikipedia.*
Bias	All codes related to bias/perceived bias (e.g., citations and sources, biased language, paternalistic attitudes)	*Because I was doing some research and I found an article that had fairly biased language, so I was like, Hey, I could actually edit this... why don't I just edit this? So, I signed up and ever since then I've been kinda looking at articles that I normally look at and editing where I may have some more expertise than what's been added.*
Describing Wikipedia	All codes related to editors' descriptions of Wikipedia from infrastructure and tools to policies to processes to community norms and values	*One of the things is, "What would I review?" I looked through the AfD page, and, I mean, there are hundreds of AfDs to read today. So, the answer is: I wouldn't have a clue, but the only way would be to have a kind of curation effort so that an AfD related to women's health came up on the project page. There's no mechanism for that right now.*
Information ecosystem	All codes related to Wikipedia as a part of the information ecosystem (e.g., Wikipedia *vs.* other health information sites, Wikipedia and Google, Wikipedia and Siri, Wikipedia articles becoming commodities)	*So, you know, WebMD has—their funding model is that they create information and then they sell the readership to advertisers. There's concern with respect to WebMD that not only are their advertisers, but the*

Category	Associated codes/concepts	Example
		advertisers tend to impact the article content itself. There was a nice write up in The New York Times about that. *The NIH is a great website. The difficulty is that the NIH's scope is fairly narrow, and their content isn't very well-organized. So, you know, they have content, but it doesn't mesh together very well at this time.*
Envisioning audience	All codes related to how editors envision their audiences	*Right, right. I always try to pretend that I have that problem. And then I pretend that like, Wow, I just left the doctor's office, and this is what he said.*
Women's health on Wikipedia	All codes related explicitly to women's health on Wikipedia (e.g., how it is defined, status of content)	*There are also issues around the terminology because you can have—you know, you can have ovaries and you can have other such reproductive organs if you don't identify as a woman, but you still have those organs. You can also be intersex and have a mixture of different things. So, the name "woman's health" is kind of misleading and not really appropriate.*
Gender gap	All codes related to comments about Wikipedia's participatory gender gap and assumptions about related content gaps	*WikiProject Military History meshes up more nicely with the demographics of Wikipedia, so it's naturally a very popular topic.*
Medical professionals	Explicit references to medical professionals whether or not they are also Wikipedia editors and/or men; includes positive, negative, and neutral comments	*Oh, the content was horrible. And biased. It seemed to be written from a male doctor's view. Hey, I wrote the article on Sexism in medicine too, by the way.*

For some excerpts, I applied several codes; therefore, the excerpts span more than one category. For example, the following excerpt spans *Women's health on Wikipedia*, *Content gaps*, *Bias*, *Gender gap*, and *Medical professionals*: "Oh, the content was horrible. And biased. It seemed to be written from a male doctor's view. Hey, I wrote the article on Sexism in medicine too, by the way." I attended to these kinds of categorical intersections during analysis and in the discussion below.

Finally, because the population (i.e., explicit members of WikiProject Women's Health) was so small, I was unable to sample until I reached theoretical saturation; however, I was able to identify a few negative cases in the data. Overall, my aim was to create categories from the interview data and analyze relationships between these categories while attending to the lived experiences of all participants (Charmaz, 1990); generating substantive theory was *not* my aim.

Document analysis

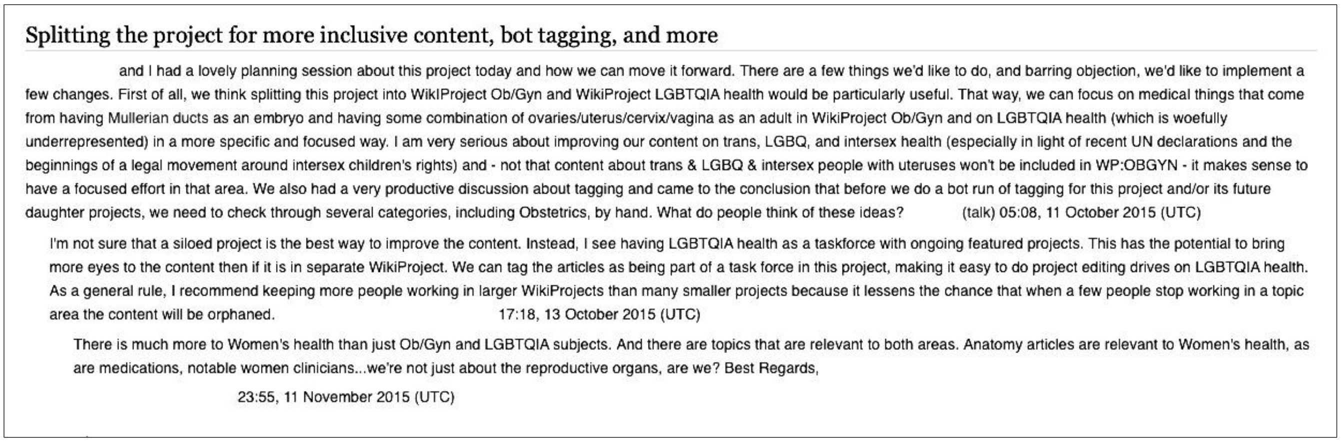
In this study, I used documents (e.g., Wikipedia project pages, revision histories, talk pages) as supplementary data to triangulate interview data and to understand the context of women's health information on the English language Wikipedia (Bowen, 2009).

Data collection

To begin, I manually reviewed and took screenshots of every page belonging to WP WH, including talk pages and revision histories. As I conducted interviews, I broadened my review of documents based on feedback from interviewees and references they made during interviews. In total, I analyzed 16 documents and reviewed dozens more. All of these documents are publicly available, but I do not include editors' usernames in the write-up below.

Data analysis

After I collected the 16 documents (or pages) as screenshots, I imported them into NVivo where I used open coding. At the same time, I wrote memos to identify emerging themes across the documents and interview data. I was particularly interested in passages in which Wikipedia editors discussed how to scope WikiProject Women's Health (see Figure 2.5), including excerpts from WikiProject Council proposal pages and Category pages (e.g., Category: Women's health) as well as the Administrator's Noticeboard, where editors discussed banning an editor from editing content related to women's anatomy and health.



Splitting the project for more inclusive content, bot tagging, and more

and I had a lovely planning session about this project today and how we can move it forward. There are a few things we'd like to do, and barring objection, we'd like to implement a few changes. First of all, we think splitting this project into WikiProject Ob/Gyn and WikiProject LGBTQIA health would be particularly useful. That way, we can focus on medical things that come from having Mullerian ducts as an embryo and having some combination of ovaries/uterus/cervix/vagina as an adult in WikiProject Ob/Gyn and on LGBTQIA health (which is woefully underrepresented) in a more specific and focused way. I am very serious about improving our content on trans, LGBQ, and intersex health (especially in light of recent UN declarations and the beginnings of a legal movement around intersex children's rights) and - not that content about trans & LGBQ & intersex people with uteruses won't be included in WP:OBGYN - it makes sense to have a focused effort in that area. We also had a very productive discussion about tagging and came to the conclusion that before we do a bot run of tagging for this project and/or its future daughter projects, we need to check through several categories, including Obstetrics, by hand. What do people think of these ideas? (talk) 05:08, 11 October 2015 (UTC)

> I'm not sure that a siloed project is the best way to improve the content. Instead, I see having LGBTQIA health as a taskforce with ongoing featured projects. This has the potential to bring more eyes to the content then if it is in separate WikiProject. We can tag the articles as being part of a task force in this project, making it easy to do project editing drives on LGBTQIA health. As a general rule, I recommend keeping more people working in larger WikiProjects than many smaller projects because it lessens the chance that when a few people stop working in a topic area the content will be orphaned. 17:18, 13 October 2015 (UTC)
>
> > There is much more to Women's health than just Ob/Gyn and LGBTQIA subjects. And there are topics that are relevant to both areas. Anatomy articles are relevant to Women's health, as are medications, notable women clinicians...we're not just about the reproductive organs, are we? Best Regards,
> >
> > 23:55, 11 November 2015 (UTC)

Figure 2.5. A screenshot of one section from the WikiProject Women's Health talk page archive with Wikipedia editors' usernames redacted. This section contains an original post with two comments. During my analysis, I made several annotations here, including "defining women's health," "medical things," "LGBTQIA health," "legal movement," "bots," "OB-GYN," "more eyes," "reduced to reproductive organs," and "women's health as boundary object." I then compared these annotations to the codes and categories emerging in the interview data.

Findings

WikiProject Women's Health

During the course of interviews, I learned more about the project's history, members, and current status. I begin with a description of the WikiProject, including demographic information about participants.

Participant demographics

I interviewed eight of the 11 explicit WikiProject members who were active at the time of data collection. Five interviewees were women and three were men. They ranged in age from mid-20s to early 70s. Interviewees reported being well-educated with six participants having had some degree of formal medical training. Between them, they had an average of 10 years of editing experience on the English language Wikipedia (*s*=3.5). In comparison to the most recent demographic survey of Wikimedians worldwide (Galvez, 2018), my sample include a larger ratio of women to men but is otherwise representative of the global editor population (see Table 3.5).

Table 3.5. Participant demographics with assigned pseudonyms, gender, indication of formal medical training at the postgraduate level, and the number of years editing the English language Wikipedia at the time of interview.

Pseudonym	**Gender**	**Formal medical training?**	**Years on EN**
Eileen	Woman	N	11
Henry	Man	Y	11
Kate	Woman	Y	2
Matthew	Man	N	12
Navi	Woman	Y	8
Sara	Woman	Y	11
Whitney	Woman	Y	13
William	Man	Y	12

The three explicit project members who did not respond to my requests for interviews were all men and included the long-time Wikipedian and Wikimedia Foundation employee who proposed the project, a medical student and Wikipedian in Residence, and a Wikimedia Foundation employee and site administrator. Two of these project members are still active, explicit members. As of May 2019, four of interviewees are still explicit, active members.

Project history

One of my goals in studying WikiProject Women's Health was to understand its history—how it came to be, who started it, and why. Sara and Matthew shared different parts of the project's origin story with me. Sara recalled:

> *I know that I was planning to start a Women's Health project and then [Editor 1] created the page before I could get to it, but I was there at the outset. I actually made [Editor 2] do all of the tagging for me. I was like, "Do you want to write about women's health? And he was like, "I don't know anything about health." I was like, "You wanna tag a thousand articles?" And he was like, "Sure!" We were in [city] for some reason, and I was hanging out with [Editor 3] and [Editor 4], and we were writing about cancer, and we were like, "[Editor 2], go tag!" and made him tag for a couple of hours. It was great. So, yeah, I've been there since the beginning.*

As Sara reported, only a handful of editors were involved in creating the WikiProject and, according to revision histories, user pages, and user contributions, all of them were prolific, experienced Wikipedians. Interestingly, as Sara noted, the founding editors were also all co-located and had established working relationships at the time the project was created. Matthew, who was attending the same Wikipedia event as Sara, corroborated Sara's story. According to the revision history of WP WH, the project was created in May 2015 eight days after it was proposed on the WikiProject Council pages. In July 2015, the project adopted tools provided by WikiProject X—"an initiative seeking to improve and streamline these WikiProjects that they may better serve their purpose, through research, design, and experimentation."[37]

Given what I learned from Sara and Matthew, I asked interviewees why it had taken so long for editors to create WP WH. Matthew offered the following hypothesis:

> *So, my impression on it—and I don't really know enough about the WikiProject Medicine to say whether this is true, but my impression of it is that WikiProject Medicine already had a lot under their scope—since they do all of medicine—and because Wikipedia, in general, trends male, issues having specifically to do with women I gather don't really get as much of the spotlight. For example, there's no Wikipedia article on period tracking. That's probably a notable topic.*

Here, Matthew makes a direct connection between the demographics of Wikipedians ("trends male") and content gaps ("there's no Wikipedia article on period tracking"). Similarly, Navi suggested:

> *It could be [it took so long] because not many people are interested to read about women's health, to look at—not many Wikimedians are working on women's health. Not many people are, like, writing controversial things over there. So, when you write something controversial, you attract a lot of people. When you are writing science, you are just writing the facts, and you do not have any opinions to push there, so articles related to science in general create less of a fuss and less talk page discussion than articles related to personalities and people.*

Henry echoed Navi's observation about the role of controversy:

> *A great portion of the editing community's time is spent on a very small number of articles that are typically controversial, yet the broad, non-controversial aspects of medicine generally are often poorly followed and, you know, not as in-depth and not as well-written and not as well-referenced.*

Other interviewees also commented on potential relationships between gender, content, and controversy, explaining that: the community of editors who edit medical and health related content in general and as it relates to women's health is relatively quite small compared to the larger editing community; they think there may be a relationship between the participatory gender gap and women's health content; they perceive controversy as a factor that drives editing and some perceive women's health—an area in which "you are just writing the facts"—as not as controversial. (This is a comment I return to below and in Chapter 8.)

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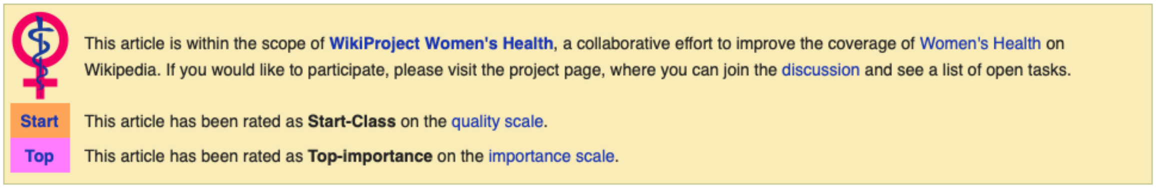
[37] See https://en.wikipedia.org/wiki/Wikipedia:WikiProject_X

Discovering and joining the project

When I spoke to project members who were *not* involved in the creation of WP WH, I asked how they discovered and joined the project. William said he discovered the project when he noticed the WikiProject Women's Health template (see Figure 3.5) on an article talk page:

> *Well, I mean, I wasn't even aware that it existed—well, it didn't exist until about a year ago. Earlier this year, I guess I came across it on an article talk page, you know, it was tagged, saying "This article falls under the scope of WikiProject Women's Health." And I thought, "There's a WikiProject Women's Health? I didn't know that."*



This article is within the scope of **WikiProject Women's Health**, a collaborative effort to improve the coverage of Women's Health on Wikipedia. If you would like to participate, please visit the project page, where you can join the discussion and see a list of open tasks.

Start This article has been rated as **Start-Class** on the quality scale.

Top This article has been rated as **Top-importance** on the importance scale.

Figure 3.5. A screenshot of the WikiProject Women's Health template applied to articles designated as "within the scope" of the project. William learned about WP WH when he saw one of these templates on an article talk page.

While Kate said she could not remember how she found out about the project—"I was just kind of looking, and I clicked through, but quite honestly, I can't remember"—she recounted that she did have specific reasons for joining:

> *I wanted to get more involved with the Wikipedia community as a whole—just to learn—I just kinda wanted to learn how it works—both the inner workings and the technical aspects of how Wikipedia—you know, the different ways of how to edit a page and just the nitty-gritty little technical stuff. So, yeah, that's why I joined the project.*

Whitney compared WP WH to other existing projects, such as WikiProject Reproductive medicine and WikiProject Sexuality, saying "I think this one is much more straightforward, working on women's health." Whitney also mentioned WikiProject Reproductive medicine "was absolutely dead" and that Wikipedia did not have an article for pediatric gynecology before members of WP WH created it: "We were really lacking in what we would call approachable gynecological content on Wikipedia, and we wanted to make a point of having people together working on it." She continued:

> *So, I was interested to see that we were not looking at things—we were not covering things in-depth. Which I felt like was partially—probably a lot because women weren't here. I mean, people do write about what's going on in their lives and what they're encountering. So, if we had many fewer women here who were pregnant then we would have fewer women writing about pregnancy or aspects of pregnancy, or we had women going through menopause less or having cancer less, then you're going to have fewer people writing about those topics. That was my view as to why we were very slow in getting those to be good articles.*

Like Matthew, Navi, and Henry, Whitney connected the participatory gender gap on Wikipedia to gaps in content and joined WP WH because she was motivated to do something about it. Below I say more about editors' motivations to create, edit, and curate women's health content on Wikipedia.

The project today

Despite the initial activity around the creation of WP WH in 2015, interviewees consistently reported a lack of continued activity after the project was established. For example, when asked about her involvement in WP WH, Eileen remarked: "WikiProject Women's Health is pretty much dead in the water." Similarly, William said:

> *I've written a fair bit of content on women's health and, obviously, a major article on it. But, have I gotten anything out of being part of the project? The answer would be obviously "No" because even though I've asked a few questions on the talk page, I've really gotten nothing back at all. There's no engagement with the other people.*

A review of project pages confirms Eileen's and Matthew's assessment: the main project page (Wikipedia:WikiProject Women's Health) has been edited 51 times since it was created in May 2015, and all but two of these edits were made in 2015. Though the talk page for the project evidences more activity, conversations between editors (defined as at least one comment per original post) began to dwindle in September 2016. Since late January 2018, posts to the project talk page have not received any replies. The most recent conversations (as of May 2019) on the project talk page include an invitation to an edit-a-thon posted in June 2018 and a note, posted in November 2018, asking project members to weigh in on a discussion about merging the *Hysteria* and *Female hysteria* articles.

In my experience, when I joined the project as an explicit member in October 2018 and had an issue with the icon displayed next to my user name, my requests for help remain unanswered despite the fact that I directly pinged (i.e., used @ to notify) a specific editor and asked for help. I wrote the following in my fieldnotes:

> **3 October 2018**
>
> Joined WP Women's health. Used image of Meeko I had previously uploaded to Commons. Noticed the thumbnail feature isn't working—the size isn't right, but I don't know how to fix it. Also noticed that joining was easier via a Wizard that I assume is a part of WikiProject X. My name won't show on the list until ~1 hour according to the Wizard. (Update: It took only ~5 minutes.)
>
> Looked at Stub articles that need work. Looked at list of tasks of articles to be created, but they are all about pregnancy and seem a bit overwhelming right now. I'll need to set aside time.
>
> Added WP Women's health userbox to my user page.
>
> I deleted the link to the image file, but there's still a formatting issue, and I can't figure it out.
>
> I added a note to the talk page, pinging [Editor]. I realize this is something I'm able to do only because I have some Wikipedia experience. I'm not sure what a new user would do.
>
> […]
>
> **7 November 2018**
>
> I figured out how to fix the formatting issue by using the Visual Editor. Still no reply to my talk page comment, which reinforces interviewees' comments re: WP Women's health being largely inactive.

As of the writing of this chapter (May 2019), an explicit project member who joined after I conducted interviews posted a few announcements to the main project page and fixed the Tasks module with the following note: “Rather than remove the tasks section entirely, I’ve just removed the content from the transcluded page[38] which no longer seems to be being updated.” She is the only editor who has been active on WP WH project pages since November 2018.

My engagement with WP WH and the data above also confirms Navi’s account of why activity on the project has declined:

> *So, I think it was that we just started a project, we all signed up, but nobody was ready to push it forward, nobody was really ready to find tasks within—sub-tasks within the project which everybody can take up. So, it was like, you just signed up for something and then there’s no follow up. I would say that that happened in my case. I wasn’t following up much on WikiProject for women’s health because I did not have any motivation to continue. I signed up because everybody signed up, and I was very interested in the cause. But I did not have sufficient time and resources for propelling the project forward, so I was looking for leadership from somebody else who would give tasks for me, put up tasks on the project page, which I can just look up and then follow. But that did not happen. That’s probably a reason why the project would not gain as much momentum as it should have.*

In summary, WP WH was founded by a small group of experienced Wikipedians who were co-located and who had prior working relationships, and—at the time of the interviews—the majority of explicit, active project members evidenced a high degree of medical expertise. Project members who later joined the project reported stumbling across it and expressed a variety of motivations for joining. Finally, the majority of interviewees perceived the participatory gender gap, the role of controversy, and/or a lack of leadership as contributing to the decline in project activity and a general lack of interest in creating women’s health content on Wikipedia.

Defining women’s health

As I discussed in Chapter 2, *how* women’s health is defined and *by whom* has a significant impact on who is made visible and, subsequently, whose needs are prioritized and who receives care. In the following section, I share findings about how editors involved in WP WH define women’s health.

What is women’s health?

Matthew was the first interviewee to direct me to the project’s archived talk pages, which document discussions about how WP WH decided to define women’s health and subsequently scope the project:

> *I think [the conversation about scoping] did take place on the project discussion page. It might be in the archive, but looking at it now, the archive isn’t linked to it for some reason. So, if you just type /Archive1 after the link, then you’ll find it. There is, in fact, a section that is called Scope. Looking at… it’s got discussion now. It more clearly—they actually discuss what the*

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[38] A transcluded page is one that has had its content included in another page using a reference: “In Wikipedia transclusion, the MediaWiki software will refer to the content of one page, the template, for inclusion into the content of any other page, the target page.” See https://en.wikipedia.org/wiki/Wikipedia:Transclusion

> *particular scope is, and they more or less decided that things having to do with what could be called reproductive health would be more in scope. I think they wanted to include other things as well, but they were kind of concerned about the scope being too big or doing things that are better suited for other WikiProjects.*

As Matthew noted, early in the project, editors (not all explicit project members) engaged in multiple conversations about the project scope, trying to define women's health for their purposes (e.g., practical purposes like creating bots to tag relevant articles). Many of these conversations balanced ontological and pragmatic concerns. For example, editors discussed whether they should include legal and social topics (i.e., domestic abuse) in addition to medical topics (i.e., conditions and diseases). One editor asked a series of questions, including:

> […] are we focusing on cis-women's health issues or including trans-women's health issues as well? Sometimes they intersect, but sometimes they don't, and I think it would be better to clarify this part of the scope early on.

Another editor answered, commenting on the dearth of information about trans health on Wikipedia and suggested addressing some aspects of this topic was within the scope of women's health:

> So on the topic of trans health, I think including articles relating to trans women is important. There isn't currently a full article on transgender health (there really should be), but articles like trans women, hormone replacement therapy (transgender) and others should fall under our scope.

Relatedly William, an editor who committed hundreds of hours to improving the *Women's health* article, said: "Someone wrote on the project talk page, 'Well, what would be in it [the Women's health article]?' That's what I'm trying to find out! Part of this project that I'm working on, you know, is to find out what actually is out there."

Beyond the initial conversations about what is and is not within the scope of WP WH, editors continued to engage in negotiation as they decided whether to apply the project template and related category tags to new articles, or which articles to translate from English to other language Wikipedias. For example, Henry said he agrees "completely" with women's health being defined more broadly and offered a perspective about what is most important for other language Wikipedias:

> *So, what we [the Translation Task force] have is several campaigns. Our first was one on vaccines, and our next will be about women's health issues, and we're discussing what will we promote in this campaign for translation to other languages. One the articles we're looking at translating is the article on burns, and, you know, from a Western point of view, it might seem unusual why women should be—or why they might have more burns, or why it would be a women's health topic. But if one looks at Africa, one looks at Asia, women do most of the cooking. Women wear long dresses in much of the world, and those dresses catch fire because people are cooking with open flames. So, burns are more of a women's health topic—more of a women's health issue in much of the developing world than it is in the West. So, you know, with respect to the translation project, we're viewing women's health related topics as being fairly broad in scope rather than just being sex and pregnancy related.*

My conversation with Henry then turned to how one might quantitatively establish a baseline for the number of articles dedicated to women's health on the English language Wikipedia: "Yeah, and, you know, the controversy becomes: What counts as a medical article? What counts as a women's health medical article? What counts as a men's health medical article? You know, these categories don't have sharp boundaries."

Henry makes an interesting point: women's health does not have "sharp boundaries" and neither does Wikipedia's category system. Although women's health articles on Wikipedia include links to related items in Wikidata[39], and Wikidata includes links to International Classification of Diseases, 10th Revision, Clinical Modification (ICD 10) and Medical Subject Headings controlled vocabulary (MeSH) identifiers, using these identifiers to is complicated. Henry continued, thinking-aloud:

> *If we limit the group of articles we want to look at to disease related articles that have ICD 10 codes, then the problem is solved. Because ICD 10 codes—their codes are organized by specialty, and Wikidata—this is something I worked on with [name's] lab a while ago, we basically created a tool because ICD 10 codes are organized by specialty, all the As are one specialty, all the Gs are one specialty, all the Hs are one specialty, and that's how we added that field to Wikidata. So, for example, if you look at Cervical cancer, what specialty comes up? The field comes in as Oncology, and that's because the ICD 10 code is within the Oncology codes, so a C for Oncology. But you can use those codes to give you a grouping—so I guess the question is, will they have a grouping for… I'm not sure if that will solve the problem.*

But, as Henry observed, using ICD 10 codes is flawed, particularly because these codes were created and are used primarily for medical billing purposes. Only MeSH has a code for women's health: D016387 - *The concept covering the physical and mental conditions of women*. However, this code is not consistently included in Wikidata for all women's health articles. Furthermore, as Henry and I discussed, how would one categorize a sexually transmitted disease like Chlamydia that is more likely to impact women than men?

> Henry: *Yeah, there's a lot of health topics that would overlap between the two. Like Chlamydia? Is that a women's health article or a men's health article?*
>
> [I describe how I operationalized categories based on prevalence for articles like *Migraine*.]
>
> Henry: *I don't know the prevalence of Chlamydia.*
>
> [Henry searches for statistics about the prevalence of Chlamydia.]
>
> Henry: *So, 4.2% of women and 2.7% of men.*
>
> Amanda: *So, one could argue that it's more prevalent among women and, therefore, more of a women's topic. But I would guess that most STDs and STIs have higher prevalence among women due to physiology?*
>
> Henry: *Yep, so, yeah, if a HIV infected man has sex with an HIV negative woman, the woman has a greater chance of getting HIV than if an HIV negative man has sex with an HIV positive woman.*

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[39] Wikidata is a common, collaboratively edited, and open document-oriented database maintained by the Wikimedia Foundation. Each article on the English language Wikipedia can be paired with a Wikidata item.

As of the writing of this chapter (May 2019), the *Chlamydia infection* article is not categorized as being within the scope of WP WH and the MeSH code for women's health (D016387) has not been included in the Wikidata item for the *Chlamydia infection* article.

In summary, defining women's health is a necessary and continuous negotiation among the editors who are involved in creating, editing, and curating women's health information on Wikipedia. Although they can appeal to the authority of and reference exogenous sources (e.g., ICD 10, MeSH), these classification systems are flawed and, understandably, present a medicalized view of women's health that often lacks nuance influenced by social and cultural contexts as well as the situational awareness that projects like the Translation Task force must leverage to make decisions about what counts and for whom. Moreover, Wikipedia is a more agile site of knowledge production than exogenous sources in that editors—particularly the small group involved in writing women's health content—can decide together how to define their scope and then adjust as-needed whereas controlled vocabularies are slower to change. For example, although the World Health Organization manages the base codes for ICD and countries are able to modify the codes to suit their needs, the development of the newest version of ICD codes took more than a decade.

Writing women's health content

During interviews, I asked participants about their motivations for writing women's health content on Wikipedia. I also asked them how they envisioned their audiences. Although I did *not* ask them who is qualified to write about women's health, their thoughts about this topic emerged as a dominant theme across interview transcripts and during document analysis. Additionally, during the midst of this study, an editor was banned from editing articles about women's anatomy and health, which underscored the relevance of the question, "Who can write about women's health on Wikipedia?"

Who can write about women's health on Wikipedia?

According to some interviewees, writing about women's health requires some degree of domain-specific expertise and the ability to thoughtfully evaluate what does and does not count as evidence. As Sara said:

> *People just don't know what the fuck they're talking about, and they don't know how to read articles, and they don't know how to summarize things, and they don't know what's important and what's not, and they meddle. Then good stuff—I feel very protective about women's health articles because… I say this lovingly as someone who was once […] editing Wikipedia not knowing what the fuck she was doing—people who don't know what they're doing should stay away from medicine. I don't care what else they write, but they should stay away from medicine because it has a very big impact on people. I'm always—this goes against everything else about my editing philosophy that it should be open, and that people should stick their hands in and get dirty and blah, blah, blah. But medicine, you should know what the fuck you're doing.*

Feeling "very protective" about articles is not unusual; territoriality on Wikipedia is a common phenomenon that has been investigated by other researchers (e.g., Thom-Santelli, Cosley & Gay, 2009; Thom-Santelli, Cosley & Gay, 2010; Menking, Erickson & Pratt, 2019). Sara's motivation for being territorial about women's health articles stemmed from her medical expertise, experiences as a long-term editor, and her concern about how medical articles impact people. Although, according to Sara and other participants, formal medical training is not required to edit women's health content, the ability to read, understand, summarize, and evaluate medical information is. For example, Whitney shared:

> *It's a little bit of a problem because the people who tend to be activists often rely on information that is somewhat sensational that maybe they have collected themselves, or something that supports their opinion. That's what activists and advocates tend to do. So, I feel like the enthusiasm and the intent of advocates is really good, and I really like to try to channel that energy toward stronger academic sources—away from maybe their own websites to something that is probably stronger if they use it. So, I know a lot of people get turned off when they're told, "No, you can't use this," and they feel like it's because they're being treated unfairly or something like that. We try really hard to explain. A part of what I want to try to do because I've been very involved with working on medical stuff for a while is to try to be the go-between between people who have their strong opinions and what—how it should reflect probably a view I share, but they're not necessarily using sourcing that is what we would consider strong.*

Here, Whitney expresses a compassionate view towards "activists and advocates" and discusses how she has voluntarily taken on the job of being a "go-between," even pointing people to "stronger academic sources." In this sense, Whitney has, indeed, taken on the role of an unpaid medical librarian. Although Whitney has formal medical training, she expressed an openness to "alternative points of view":

> *I don't think that women's health is even one of the biggest issues within those areas. Alternative health is like one of the biggest controversial areas on Wikipedia, and it has been for a really long time. Back when I was [working on a project], there was a group of editors on Wikipedia English who essentially wanted to shame people off of Wikipedia if they have alternative points of view. I thought of it as clearly being a blind spot because so much of Western medicine is so poorly researched, so people do battleground around this issue [alternative health] a lot.*

During our conversation, Whitney shared how her daughter had decided to have a water birth and how Whitney was "unsure" about this decision but trusted her daughter's midwife and "read studies on it [water birth] and understood how in other parts of the world, including the U.K., that they were much more common, and they key issue was having someone who was experienced who knew what they were doing." We then talked about the use of ginger for nausea during pregnancy, and Whitney said: "So, fairly recently there was something on Cochrane—they did a review—they've been doing reviews of just general nausea during pregnancy and what's effective and what isn't effective—and it's been studied very little." Similarly, Sara said she is open to the inclusion of alternative health information if it is contextualized:

> *I don't have a problem with alternative health provided that it's, you know, not dangerous. There's a lot of alternative health stuff out there that's just straight up dangerous. Like, advocating for homeopathy or faith healing—that stuff. You know, stuff like herbal medicine should be included, absolutely. Traditional knowledge. I think it should be contextualized the way that. "This is the allopathic way of treating things. This is how Chinese herbs are used to treat this thing. These are the herbs used in traditional Western medicine. Here's some studies showing their efficacy or not." That's ideal for me. I don't think it should be excluded entirely.*

Like Whitney and Sara, William has formal medical training, and he also expressed an openness to other kinds of information sources and interpretations. For example, during our conversation about a lack of global perspective on Wikipedia, he said, “If you don’t change what your source of information is, then there’s not going to be room for a different perspective.” The problem, of course, is that women’s health—much less alternative approaches to women’s health—is understudied in general. As Whitney said when she concluded our conversation about alternative practices and women’s health, “All of the women have always just figured it out.”

The banning of an editor

Related to this question (“Who can write about women’s health?”), is the fact that Wikipedia administrators banned an editor (hereafter referred to as Editor 0) from editing articles about women’s anatomy and health during the midst of data collection for this study. In March 2018, an editor (hereafter referred to as Editor 1) posted to the Administrator’s Noticeboard about Editor 0’s editing of medical and anatomy articles, writing:

> This report is about about [*sic*] our health articles being some of our most important articles and [Editor 0] having repeatedly been a detriment to these articles. The fact that she is a part of WP:Visiting Scholar (although she’s not a scholar) makes it even more essential that she not be a detriment to our health articles or topics (some of which she creates) because students are sometimes referred to her or look to her edits to learn. We cannot have editors learning and taking on this style of irresponsible and error-proned [*sic*] editing. Below are examples of [Editor 0’s] editing, from most serious to least serious, that really do show that more competence is required to edit in these areas.

Here, the phrase “more competence is required” is hyperlinked to *Wikipedia:Competence is required*, an information page that supplements the *Disruptive editing* page, which is a guideline. The former page reads in part:

> Many editors have focused so much on this tenet [Assume good faith] that they have come to believe that good faith is all that is required to be a useful contributor. Sadly, this is not the case at all. Competence is required as well. A mess created in a sincere effort to help is still a mess. For that reason, it can become necessary for the community to intervene when an editor has shown, through a pattern of behavior, the likelihood that they are not capable of contributing in a constructive manner.
>
> Everyone has a limited sphere of competence. Someone may be competent in, say, nuclear physics but incompetent in ballet dancing or vice versa. Some otherwise competent people may lack the skills necessary to edit Wikipedia. Rather than labeling them as “incompetent” in the pejorative sense we should ease them out of the Wikipedia community as graciously as possible and with their dignity intact.

Competence is then defined by what it is and is not; the ability to read and write in English, understand and assess the reliability of sources, communicate with other editors and abide by consensus, and understand one’s own limits fall under this informal definition of competence. [40] Editor 1 provided 11 instances in which she perceived Editor 0 to show a “lack of competence,” ranging from confusing a mucous membrane with a mucous gland to “being defensive” about edits to using sources behind paywalls. Multiple editors became involved in this conversation. They debated whether Editor 0’s mistakes outweighed her content contributions (“[she] has created and improved a huge number of medical articles”), whether she was qualified and would benefit from mentorship (“Do we know what her qualifications are? Is there a role for mentoring?), and whether censuring Editor 0 was an example of a gendered double-standard (“I am also concerned about a double standard in restricting one medical editor, when equally dangerous and egregious editing has occurred […] by three male medical editors, who […] have not been called to task...”).

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[40] See https://en.wikipedia.org/wiki/Wikipedia:Competence_is_required

Editor 0 weighed in from time to time, saying she had some “family and personal issues” she had wanted to communicate via email but had been informed (like I was; see Chapter 4) that communicating off-Wiki was considered “unacceptable.” Finally, after a week of discussion, Editor 0 was topic-banned from editing and/or commenting on “health and medical topics, including anatomy and sexuality, broadly construed” and banned from interacting with Editor 1 who had brought the matter to the Administrator’s Noticeboard. In the end, the editors who participated in the debate decided that the contributions of Editor 1 (“a known good contributor to medical articles”) and Editor 0’s mistakes outweighed her work; but, perhaps, more interestingly, many of the editors who took part in the conversation decided they did not like Editor 0’s “behavior” as expressed in at least three separate comments about a “side” of her:

> She can be a good contributor, but there is this obstinate and even nasty side of her as well.
>
> She also has an ugly side […].
>
> [Editor 0] has something like a rebel streak that can be dark sometimes […]

What is interesting about these comments is that Wikipedia has a history of looking the other way when men evidence “obstinate,” “nasty,” “ugly,” and “dark” behaviors. Take, for example, one woman Wikipedian’s study of the accepted use of the word “cunt” as a gendered insult on the site.[41] Furthermore, it seemed to be Editor 0’s lack of expertise as a Wikipedian as well as her domain-specific fumbling that tipped the scales toward a topic ban. Perhaps Editor 0 came to Wikipedia too late? As one editor commented on the Administrator’s Noticeboard, “Maybe the situation was different ten years ago, when WP was still something of a novelty and desperately lacking content, but now that we’re invariably at the top of the search results and millions of readers are depending on us, accuracy must be prioritized over comprehensiveness.” Indeed, Wikipedia often tops Google search results and informs the responses of voice assistants like Siri and Alexa. But what does it mean to prioritize “accuracy…over comprehensiveness” when it comes to women’s health information?

In summary, the questions then become: What is the most basic requirement for writing about women’s health information on Wikipedia? Is being a woman enough? (The answer is “No,” according to participants’ responses and as evidenced in the case of Editor 0.) Does one need to have formal medical training? If so, what kind of medical training? If so, how much medical training? Does one need *only* to have access to and the ability to understand and evaluate medical literature? What does “competence” mean when it comes to writing women’s health content on Wikipedia—a site “at the top of search results”? I return to these questions in the Discussion section below.

Motivations for writing about women’s health on Wikipedia

Interviewees expressed a range of motivations for working on women’s health content. For some, their lived experiences motivated their contributions. For others, the topical content aligned with their vocation and/or avocation, and, for a few editors, explicit political concerns (i.e., feminist concerns) also motivated their participation. Of course, several participants reported a mixture of these motivations. Take, for example, Sara, who is a cisgender woman and a reproductive rights advocate:

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[41] See https://meta.wikimedia.org/wiki/Research:Communicating_on_Wikipedia_while_female

> *Right, my lived experience is what informed me wanting to change that [a section in a particular article], and my experience of working with hundreds of patients is what informs my writing. I want to be able to present medically accurate information in an emotionally sensitive way because there's a way to do that, and I do it every day, and it's important.*

Here, Sara shares that both her lived and embodied experiences as a cisgender woman and her experience of "working with hundreds of patients" motivates her to write women's health information on Wikipedia in a way that is both "medically accurate" and accounts for readers' emotions. Similarly, Navi's editing corresponds with her vocation, and she also reported that working on women's health articles is motivated by her concerns about the representation of women on Wikipedia in general:

> *I'm very concerned about how women are represented on Wikipedia, so for me, articles about women's health sounds very much like articles about my favorite football team. I don't like football, by the way. So, it's like—that keeps me interested. It's not hard for me at all, if you ask me. For me, it's the trouble in finding the time to sit down and get the article done. That happens as a barrier, but otherwise, I'm really very interested in writing about women's health because that comes from my background in health. It's also a learning and refreshing process for me as a physician to write more about health care topics in general.*

Whitney, too, expressed a "very strong interest in working on gender and women's issues" and talked about how she has served as a conference liaison, discussing issues like domestic violence with other members of the community.

When I asked participants why they thought it was important to include women's health information on Wikipedia given the availability of women's health information online in general (e.g., private websites like WebMD; government websites National Institutes of Health's Womenshealth.gov, MedlinePlus, and the Center for Disease Control and Prevention; online communities such as Reddit and Facebook groups), they pointed to the fact that Wikipedia does not rely on advertising, exists in more than 300 languages, is more accessible than most other websites, and strives to have a global perspective. For example, Henry said:

> *So, you know, WebMD has—their funding model is that they create information and then they sell the readership to advertisers. There's concern with respect to WebMD that not only are their advertisers, but the advertisers tend to impact the article content itself. […] The NIH is a great website. The difficulty is that the NIH's scope is fairly narrow, and their content isn't very well-organized. So, you know, they have content, but it doesn't mesh together very well at this time. […] The NIH's content is in two languages, English and Spanish. We have health care content in 275 languages. Also, the NIH is very US centric. We are working to be much more global in scope. Often the NIH will just present topics from an American perspective.*

Participants also spoke to what they perceived to be readers' expectations, noting that because Wikipedia has become such a powerful and ubiquitous resource, people *expect* to find all kinds of information there when they search for it.

Overall, despite individual differences in positionality and motives, all of the participants in my study expressed a strong sense of "doing what's right." Henry, a cisgender man, said:

> *I believe what we're doing matters. So, all the bullshit we have to deal with and all the nastiness—you know, I'm here because I believe the people of the world need us. I'm not here to become friends with [name]. I'm here to do what needs to be done. I'm here to do what's right.*

These findings resonate with prior work (e.g., Kuznetsov, 2006; Schroer & Hertel; Nov, 2007; Yang & Lai, 2010) with all of the participants but Kate (who was a relatively new contributor) performing as Wikipedia "experts" as described by Bryant, Forte & Bruckman (2005). These findings also point to opportunities for future work about how lived experiences—particularly centered on embodiment and health—shape editors' motivations to contribute and whether there is room for patient expertise on Wikipedia.

Who is the audience for women's health information on Wikipedia?

When I asked interviewees how they envisioned their audience, their responses fell into four somewhat surprising categories: (1) women seeking health information; (2) people who may learn about and/or be impacted by a woman's health event; (3) medical students and/or medical practitioners; and (4) high school students presumed to have limited access to information sources.

All of the women I interviewed reported envisioning their audiences—at least, in part—as other women seeking health information, sometimes putting themselves in the place of their readers. For example, Eileen said, "I always try to pretend that I have that problem. And then I pretend that like, wow, I just left the doctor's office, and this is what he said." Sara, too, said she thinks about the reader who may have first-hand experience with the topic:

> *Getting the [title] article fixed to acknowledge the emotions of the person reading it was such a battle. In general, there's no thought given to how the reader of the article may feel while reading it. It doesn't need to be written in the second person—or whatever people are afraid of happening. It just needs to be constructed in a way to minimize emotional trauma.*

Whitney said she too thinks about women seeking health information, but with a caveat:

> *People should not be getting their—they should not be making their life decisions based on medical content on Wikipedia. They should have discussion with their doctor or—I just have this dream that it's really being written for an employer so that when his employee comes to him and says, "I need to take off for surgery next week. I'm having this done," that they can look to see what their employee is having done, or your neighbor, or whenever someone gets awful news and are told they're going to have to come back for appointments and they need to tell their family, then their family can go and read what it's all about. You know what I mean? I think it's more for those people. So, I think it's less risky if that's the case. I don't think individual people should be using it to make health decisions. I'm hoping the world is better than that, and that their general practitioner or nurse will be their main source.*

Here Whitney expresses a concern about readers "making their life decisions" based on Wikipedia's medical content primarily due to the risk that presents. She said that, although another editor had started a campaign to prioritize editing the most popular medical articles, there were thousands of other articles that were "inaccurate or outdated." (I return to Whitney's concern about neglect in Chapter 6.) Importantly, Whitney's belief that people should be getting health information from "their general practitioner or nurse" also devalues patient expertise—"the experiential knowledge that patients have gained about effectively accomplishing the work of being a patient" (Civan & Pratt, 2007)—and elevates clinician expertise, even on Wikipedia "the encyclopedia anyone can edit."

Navi and—to a lesser degree—Sara also envisioned their audiences as consisting at least in part of medical students or practitioners particularly when it came to images, which I say more about below. Interestingly, though Henry did not say he envisioned his audience as medical students or practitioners, other participants perceived Henry as having this perspective, particularly when it came to whether the psychological and emotional impacts of health issues should be included in relevant articles. For example, Eileen said explicitly of Henry:

> *One of the ways Wikipedia is biased is they systematically discount any kind of emotional reaction to any medical condition. Does that make sense? I mean, I had to—[Henry] removed one statement that I included in the lede of [article name]. I really just worked on that one. I put in there, "profoundly affects the quality of life for women," okay? He took it out. He said, "Oh, that's—you know, your source wasn't good." So, me—me with the bad attitude—so, I find four more. And I put it right back in.*

During one of our conversations, Henry pointed me to a video about Wikipedia Zero, a Foundation project to provide Wikipedia free of charge on mobile phones in certain geographical areas[42], saying:

> *There's an amazing video up from South Africa. You might have seen it. Let me see if I can pull it up for you. It's about two minutes long, and it's by some students, some high school students in South Africa, and this is sort of who I envision I'm trying to write for when I'm working to improve Wikipedia. [...] I envision my audience as being, you know, high school students.*

Henry's response about the way in which he envisions his audience resonates with an appeal once made by Wikipedia co-founder Jimmy Wales: "I'm doing this for the child in Africa who is going to use free textbooks and reference works produced by our community and find a solution to the crushing poverty that surrounds him."[43] In Henry's case, this means he prioritizes writing medical content, which is often technical, in "easy to understand language." In both cases, the tone is paternalistic and positions Wikipedia as a kind of modern-day gospel: free knowledge for everyone but, arguably moving unidirectionally from those who are privileged to those who are less so.

Emotions and stigma

Several of the women I interviewed reported that editors who are medical practitioners are often resistant to including information about the psychological and emotional impacts of health issues. In particular, three women mentioned one editor by name, recounting multiple disagreements with him about a range of topics and articles. For example, Sara talked about how she had argued with him for months about the *Miscarriage* article:

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[42] See https://en.wikipedia.org/wiki/Wikipedia_Zero

[43] See https://en.wikipedia.org/wiki/Talk%3AJimmy_Wales%2FArchive_3#"Child_in_Africa"_quote. This quote was later removed from the *Jimmy Wales* article.

> *We had this whole long fight about where to put the emotional [impacts] of miscarriage, and I thought it was really inappropriate to put "People having miscarriage may feel sad" next to… so it was like "People having miscarriage may feel sad and have clots coming out of their vagina." "Dude, really?!" I wore him down over this and a couple of other things.*

Similarly, Eileen expressed frustration with the same editor, saying:

> *When there's an emotional reaction to a—something that a woman experiences, for some reason, the assumption is, "Well, that's not encyclopedic." What are you talking about? I'm only saying what the sources say. There is an emotional component to, I don't know, hyperthyroidism in women, miscarriage, rape. All of this other stuff. You can tell men wrote it. Like, "Okay, yeah, they have feelings, but they're not very important or encyclopedic enough to include."*

Some of the women editors I interviewed for object biographies (see Chapter 6) also shared this perspective, often linking emotions and stigma as Sara did when she talked about working on the *Intact dilation extraction* (IDX) article:

> *The emotional stuff is also difficult because there's not a lot of information out there. It's just things that are told from one person to the other. There's not a lot of information because people's emotional state is not considered relevant, which is some hot garbage. So, for example, Intact D&E is really, really stigmatized as a procedure, which is stupid for a million different reasons, but it [the article] didn't have anything about the emotional reasons as to why a parent might choose an intact D&E, you know, in a fetal anomaly pregnancy. There was just nothing about why it's good emotionally for people to do this sometimes. Most physicians won't do it because it's banned in a lot of places, but it's also more difficult for the patient. There's more time, more dilation—so it's riskier and more painful—but emotionally, you know, the ability to have an intact fetus is really important, and there are techniques that one can use, but there was no information. This can be a beneficial thing to do emotionally because the parent gets to hold their child. Not in pieces. The double whammy of stigma and emotions.*

Sara's comments contradict Navi's assertion that writing about women's health is generally non-controversial ("you are just writing the facts"), especially as an IDX procedure may be performed in the case of a miscarriage, fetal anomaly, or late-term abortion, and—as Sara notes—it has been banned in *all cases* in a number of states.

Emotional labor, burnout, and (a lack of) support

Related to "emotional stuff," participants also described the emotional labor involved in writing about women's health, how it can result in burnout, and where and how they seek support. For example, Eileen talked about why she often writes content for other projects: "Okay, you know what? You can only write about cervical cancer for so long until you need to do something else." While emotional labor and burnout on Wikipedia is not specific to writing women's health content, at the end of her interview, Sara—who edits across a range of topical areas—noted that the work of writing women's health information is particularly "overwhelming" due to the amount of content that is either missing, underdeveloped, or erroneous: "I will say that there's just so much to do, it's overwhelming. There's an overwhelming amount of work to do." Moreover, as noted above, the community doing this kind of work is relatively small given the larger editing community.

Yet, despite engaging in unpaid labor to create free health-related content, Whitney reported that experiencing burnout and subsequently taking a *wikibreak* is not always perceived as "legitimate": "With volunteer work, it's oftentimes not seen as legitimate if you want to take a break. But the level of volunteer work that I do, I have to take a break from time to time." Notably, aside from Kate, the editors I interviewed are all power users, and only Matthew did not report personal experience with emotional labor or burnout.

Considering factors like emotional labor, burnout, and the need for support also prompts us to return to the question, "Who can write about women's health on Wikipedia?" Henry argued that the claim that people do not edit Wikipedia because it is "hard" is unfounded:

> *People complain how hard it is to edit Wikipedia. You know, try submitting a paper to JAMA, or to JMIR, or to any of these publications. It takes eighteen months to get through the process. You know, version after version after version. Editing Wikipedia is easy in comparison. So, this excuse that people don't edit Wikipedia because it's hard? People do lots of things that are very, very hard. Academic publishing is ten, twenty, fifty times harder than publishing on Wikipedia. That's not the actual barrier. It being hard is not the actual barrier.*

But we know some people are better equipped to navigate these kinds of barriers—such as submitting a paper to a peer-reviewed academic journal or editing Wikipedia—because they have access to more social and material capital than others do. Certainly, the participants in my study represent a specific segment of the population; they are well-educated, have access to digital and information resources, do not have young children at home, and—with the exception of one participant—enjoy a certain degree of white privilege.

Although Wikipedia offers very little formal support, some participants reported creating and/or finding support networks for themselves offline or via other platforms. For example, Matthew said he was pretty sure "some people have Skype conversations," and Sara corroborated this, adding: "I'm also in a Facebook network that's secret that's for reproductive health advocates […] So, that's another place for emotional support." In fact, editors who write certain kinds of women's health content (e.g., controversial articles about reproductive rights) may be particularly susceptible to burnout and need additional social and emotional support—despite their positionality and privilege.

In summary, writing about women's health on the English language Wikipedia is a complex and dynamic task involving continuous negotiation within the editing community about who is qualified to contribute, who the intended audience is, and how to balance accurate medical information with emotional sensitivity, particularly when writing about controversial topics or the emotional and psychological impacts of specific diseases, conditions, and procedures. Participants reported a range of motivations—some vocation/avocation-based, some value-based, and some politically-based—but, overwhelming, the women I interviewed also talked about their embodied experiences as motivating their contributions. Finally, writing women's health information on Wikipedia can be emotionally taxing resulting in burn-out and, yet, there are no formal mechanisms for support.

Illustrating women's health

Although I had not intended to study the illustration of women's health articles on Wikipedia, five of eight interviewees reported it was difficult to find representative and appropriately licensed images to illustrate medical articles in general and women's anatomy and health articles specifically. Furthermore, while some editors expressed frustration with sexualized or exaggerated images of women's anatomy, others expressed frustration with how stigma impacts the inclusion of images related to pediatric gynecology.

Sexualized images

Articles about women's anatomy fall under the scope of women's health. Yet illustrating articles associated with women's anatomy can be tricky. Some of this has to do with the history of how women's bodies have been portrayed, sexualized, and objectified for centuries (e.g., Zimmerman & Dahlberg, 2008; Szymanski, Moffitt, & Carr, 2011), and—relatedly—some of this has to do with the images of women's bodies that are available for editors to use. For example, Whitney reported:

> *We really do need images, and we need high quality images. It's better than it used to be, but still isn't good. Many of our images that we're using on our anatomy content is really sexualized. They could very well be from porn stars or whatever. It just isn't appropriate to be used—if the article is going to be used in a medical way. It just isn't. It really kind of downgrades us. Of course, we get pushback. You know, "Wikipedia isn't censored." I'm not opposed to having—to showing vulvas with piercings and things, but when the majority of the images are pierced, you know, and shaved—it just probably does not reflect the reality of most of the world. Then, something seems to be wrong, you know, with the way we're portraying anatomy.*

One of the barriers Whitney alludes to here is that Wikipedia editors rely on images in Wikimedia Commons—an online repository of free-use images, sounds, and other media files maintained by the Wikimedia Foundation—to illustrate articles. (To be clear, images *can* be posted to a Wikipedia article page without existing in Commons, but the practice of Wikipedia rather than Commons hosting an image is an exception rather than the rule; Wikipedia is, in many ways, inextricably bound up in the infrastructure of Commons by design and by community norms.) However, Commons is notorious for hosting a large amount of amateur pornography and rumored to have administrators who are sympathetic to exhibitionism (e.g., Stuef, 2012; Morris, 2013). For example, as of May 2019, a search for "vulva" on Commons resulted in two categories: Human vulvas and Mammalian vulvas. The first category—Human vulvas—contained 11 subcategories, including "Courageous Cunts" and "Wet vulvas"; the former subcategory includes images of pierced vulvas while the latter is explicitly sexual in nature. In contrast, Whitney suggested there should be a designated image collection on Commons for editors of women's anatomy and health articles to use, adding, "We need all colors of skins of both practitioners working with clients and the patients too so that people feel welcome." However, building this kind of collection on Commons is not an easy feat.

Barriers to contributing images

There are several practical and legal barriers to contributing high quality, appropriately licensed medical and health related images to Commons that can then be used to illustrate Wikipedia articles about women's anatomy and health. First, one must have access to high quality images, which as Navi explained can be time-consuming and expensive:

> *It's that images are very rare. It requires a lot of institutional support to get even one image. So, when I worked with the department of pathology in my medical school—pathology is the study of diseases—so they have images from under the microscope. So, say they have a picture of the cancer of the ovary and they have a slide—they have slide which they put under the microscope and they look through it and they used a magnifying computer to take pictures from the slide. So, all of these processes are very expensive, and to create that slide, we need to have technicians, we need to have big processing machines, we need to use so many chemicals, and one has to wait for two weeks to get the entire process done, and then it goes to an expert pathologist, and then the pathologist has to look into it, and they have to write the description for the slide to finally conclude that it is, indeed, an ovarian cancer. So, this is not something you can—that I can do in my backyard. It's tremendously and incredibly expensive and unless we have an institution that supports this and gives us the image for free, a project like this kind cannot be done.*

Navi carefully articulated the people, equipment, and processes involved in creating one image: a micrograph of ovarian carcinoma. High-quality medical images require certain kinds of infrastructures; they cannot be generated in one's "backyard," as Navi said.

Second, even if one has access to high-quality medical images, one must (1) have permission to and (2) know how to upload and license images in Commons. Although Commons provides an Upload Wizard, the wizard does not address the complexities of consent. Henry, who has contributed images to Commons and been involved in a related lawsuit, noted:

> *You don't need signed consent for Wikipedia or Wikimedia, but you need signed consent for yourself. What I do is that I get signed consent and I keep a copy of the signed consent in a folder in my office. Plus, I put a copy of the signed consent on the patient's chart because, you know, if you run into issues, the issue is going to be between you, the patient, and your college of physicians and surgeons, or whatever your licensing body is in your country. But most people are well aware of that. Some hospitals have additional requirements. Many institutions—especially in the States—are exceedingly conservative and they have policies stating you cannot take pictures for any purpose without our [the institution's] consent. That, of course, ends it for many people.*

Third, as Henry described, there can be "personal and professional ramifications" for contributing images; more specifically, there can be legal ramifications:

> *That's the real question. That's the barrier to the images. What are the personal and professional ramifications for getting involved in this? And, yeah, you know, there are serious personal and professional and legal ramifications for donating images to Wikipedia. People will attack you for it.*

Aside from the availability of appropriately-licensed, representative images, there is also the question of who decides what is and is not inappropriate or offensive. In the following section, I discuss disagreements about images as illustrated in the interview data and document analysis.

Disagreements about images

Kate, who began editing Wikipedia when she was considering breast reduction surgery and found the text of the *Breast hypertrophy* article to be both inaccurate and offensive, said:

> *It's [the image] not representative of the vast majority of women who get the surgery. I mean obviously, I didn't have breasts that were so big that I couldn't walk around. I have a couple of friends who have had the surgery, too. As my surgeon put it, their bra sizes were "in the middle of the alphabet." So, it's like, you know, K, H, I. And that's where I was too. But to have an image that shows the complete .01 end of the bell curve, I don't know. It would be nice to see something that was more representative of the population who gets the surgery.*

The image Kate referred to is a reproduction of a painting from the public domain that features a woman reported to have had breast reduction surgery in 1849 (see Figure 4.5):

> Lu-shi, aged 42, first presented herself at the hospital, April 17; and when we were about to operate on her, after a few weeks' preparatory treatment, her impatient, opium-smoking husband suddenly summoned her home. Her husband died, and the woman returned. Dec. 24, 1849, the left breast, measuring 2 feet, 2 1/2 inches in circumference, and weighing 4 1/2 catties (about 6 pounds), was removed in three and a half minutes. In one month after, the right breast, measuring 2 feet, and weighing 5 1/2 pounds was removed in three minutes.[44]

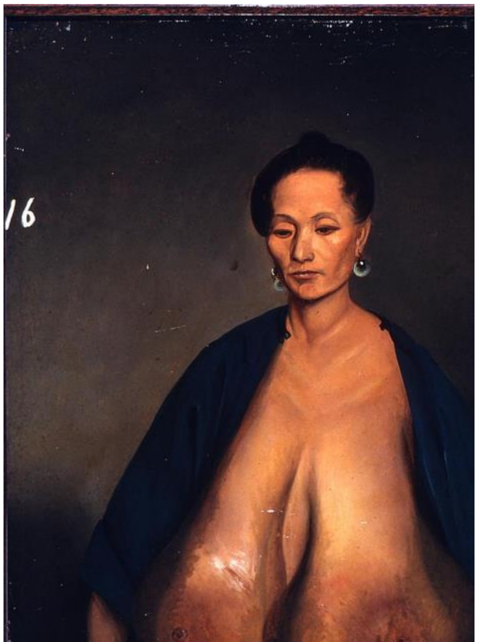

Figure 4.5. A reproduction of a painting of a woman reported to have had breast reduction surgery in 1849. This image was the only illustration included in the Breast hypertrophy article when Kate edited it. As of April 2019, this image remains in the article.

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[44] Image description per Commons (https://commons.wikimedia.org/wiki/File:1848_lam_aua_hypertrophy.jpg)

A few months after I interviewed Kate, another editor added five images to the article: *12-year-old girl with juvenile gigantomastia.jpg*; *12-year-old girl with virginal breast hypertrophy.jpg*; *Virginal breast hypertrophy in an 11-year-old girl.jpg*; *Gestational breast hypertrophy in a 30-year-old woman 25 weeks into pregnancy.jpg*; and *24-year old woman with gestational gigantomastia at 28 weeks of pregnancy.jpg*. Some of these images were removed by an editor using an unregistered IP address citing "child pornography," but they were quickly re-instated by a third editor. This cycle continued until 2017 when the images were removed by a fourth editor "due to legal concerns in some jurisdictions," according to comments in the article revision history. As of May 2019, the article still features the painting above (Figure 4.5) in addition to two illustrations, both of which are historical in nature.

Sara disagreed with Kate's comment about the images illustrating *Breast hypertrophy*. In fact, Sara argued the previously deleted images depicting pediatric instances of breast hypertrophy should be restored:

> *I'm looking at the Breast hypertrophy article. I actually really like the first two images. I like the first one because it's historic, so if you're opening the article, you're not going to get blast of something super graphic. I like the pediatric image because it shows—first of all, it's educational. It shows the ulceration, and it shows the disproportionate hypertrophic tissue. The face is obscured. There are no identifying details. That's about as good as it gets, frankly. Is it a disturbing image? Yeah. Is medicine generally also disturbing? Yes. I would love to see an image of gestational breast hypertrophy because that looks a very specific way, and that could be really, really useful. You know, I'm not a fan of—I guess the picture of—the painting, it's okay. I don't think the reported case studies—it's not a great article, but as images go, it could be worse.*

Arguably had Kate looked at the *Breast reduction* article, she may have had a different response to the images there, but Kate and Sara's conflicting opinions, the talk page for and article revision history of the *Breast hypertrophy* article, the continued inclusion of the image of the painting (Figure 4.5), and Whitney's observations about illustrations of women's anatomy on Wikipedia in general raise a series of interesting questions: Who decides which images are appropriate for illustrating women's anatomy and health articles on Wikipedia? Who determines whether the subjects of these illustrations (e.g., photos, paintings) have granted consent? Did Lu-shi grant consent in 1849? If not, despite it being legal for Wikipedians to use an image of her in 2019, should they?

Issues of consent are particularly complicated when it comes to images of minors. As Whitney discussed, many Wikipedians—particularly English language Wikipedians from North America and Europe—fiercely defend a *lack* of censorship as a key virtue (Morgan, Mason & Nahon, 2012); however, there are legal ramifications when including images of minors. An editor explains this on the talk page for *Breast hypertrophy*:

> I didn't remove the picture, though it appears somebody else did. [*Editor name*] is quite correct that we are not allowed to censor Wikipedia on the grounds of individual subjective moral values. I personally don't find the image offensive, but I think it is legally dubious. Although we do not censor, Wikipedia cannot (and does not) publish anything that is illegal in the state where the servers are based. […] If the girl is genuinely 15 years old, and the image does not portray gigantomastia, regardless of what we may subjectively think about the image or whether or not it should be on the page, it is dangerously close to breaking the law - period. The whole raison d'etre for the image being there would be false if that's just a picture of a normal topless 15 year old. This is about legality, not morality.

However, Sara pointed out that her medical textbooks are filled with images of "underaged reproductive bits":

> *I don't have a problem with images of underaged reproductive bits as long as they're anonymized and not pornographic, and they're explicitly educational. I got into a fight—not a fight—it was a fierce discussion with my friend about the image in the article Müllerian agenesis. You should look that up. It is a graphic medical image. The lede image. But it's, you know, he was like, "Why is there that image there? It looks like it's just a normal image." And I was like, "First of all, she has no vagina, and that's why the image is there. You cannot see it." And I think that images like that are really important to show what it looks like to people. That's really important. And there are a lot of pediatric conditions that we don't have images for—whereas my textbook is just filled with them.*

Sara's argument resonates with participants' answers to my question about how they envision their audiences. For example, for editors who imagine their readers as medical students or practitioners, certain kinds of images are not only appropriate, they are necessary.

In summary, illustrating women's health content on Wikipedia is a complicated task on many levels. It relies on external infrastructures for both securing and hosting images (e.g., institutional support, complicated and expensive infrastructures, Wikimedia Commons), requires a personal and, sometimes, professional willingness to risk criticism and/or litigation, and means that specific choices of images must be negotiated both socially and legally. These hurdles are even more significant when illustrating medical content related to minors.

Discussion

To interpret the findings presented above, I rely on the concept of *rhetorical situation* to unpack participants' perceptions and experiences of creating women's health information on Wikipedia. I also discuss how the design of Wikipedia impacts the success of WP WH and the creation, curation, and maintenance of women's health information in general. Finally, I argue an editor's beliefs about gender—rather than their own gender identity alone—is an interesting factor to consider when interrogating relationships between the participatory gender gap and content gaps assumed to be gendered (i.e., topics assumed to have some kind of gender valence).

Rhetorical situation

A *rhetorical situation* as defined by Lloyd F. Bitzer (1992)[45] is:

> […] a complex of persons, events, objects, and relations presenting an actual or potential exigence [an imperfection or something waiting to be done] which can be completely or partially removed if discourse […] can so constrain human decision or action as to bring about the significant modification of the exigence. (p. 6)

More simply put: a rhetorical situation is any that involves at least one speaker and an audience and that requires communication for some kind of change to occur. For example, Bitzer writes that a lead fisherman instructing other fishermen to throw nets and, thus, catch fish and an attorney presenting closing arguments in defense of her client in hopes of persuading the jury in her client's favor are both rhetorical situations (p. 5-7). So, we can think of Editor 1's post about Editor 0 to the Administrators Noticeboard as an example of specific rhetorical situation on Wikipedia that involved a range of "persons, events, objects, and relations" in response to the exigence of what she perceived to be Editor 0's problematic editing. But we can also stretch Bitzer's concept to think about Wikipedia itself as a rhetorical situation. That is, we can imagine that Wikipedia (wikipedia.org) exists in response to today's demand from a range of audiences (e.g., individual readers, news organizations, search engines, intelligent assistants) for online information about a range of topics, including women's health. While imperfect, Bitzer's model of a rhetorical situation provides us with three lenses through which we can view the findings presented above.

Exigence

As noted, an *exigence* (in the case of a rhetorical situation) is an imperfection or something wanting to be done. Bitzer goes on to say that an exigence that cannot be modified (e.g., death, winter, natural disaster) is not a rhetorical exigence, and an exigence that can be modified by something other than rhetoric—for example, an individual's application of a tool without any discourse—is also not a rhetorical exigence (p. 6). From the findings in this chapter, it is clear that women's health information on Wikipedia can be modified and requires discourse to do so. So, what is the exigence to create women's health information on Wikipedia? When I asked participants why it is important to include women's health information on Wikipedia given the multiplicity of other online information sites about the same topic (e.g., WebMD, CDC and NIH sites), they said Wikipedia is more accessible, covers more languages than other sources, informs Google search results (though they are not sure exactly how this happens), and does not rely on revenue from advertisers. In our conversations, however, and based on the data I collected, I would argue that the urgency of these exigencies varies. The banning of Editor 0,

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[45] Richard E. Vatz (1973) disagrees with Bitzer (originally published in 1968), arguing that the rhetor creates the exigence and, thus, the rhetorical situation. Barbara A. Biesecker (1989), echoing Derrida, argues the rhetorical situation and audience influence one another and are not binary or stable: a rhetorical situation is not a "simple linear process by which one individual attempts to influence others, but rather a complex interactive process whereby persons and collectivities articulate their shifting identities to each other within changing historical circumstances" (p. 215). Furthermore, there has been a significant amount of work done about *digital rhetoric,* including Douglas Eyman's 2015 book *Digital Rhetoric: Theory, Method, Practice*. Though Biesecker's model is more nuanced and more in line with my epistemology and Eyman's work is more recent, I have chosen to use Bitzer as his is a highly influential text, is more simplistic in its approach, and more applicable to Wikipedia (*vs.* a strictly social media platform like Twitter); therefore, it affords more clarity for this study.

in particular, offers an interesting case in which the urgency of resolving a conflict through discourse overtook the urgency of creating accessible women's health content. Also, as noted in the findings above, writing and illustrating women's health content on Wikipedia is a complex, dynamic, unpaid, and—at times—emotionally taxing endeavor; it is, as Bitzer would say, a complex and loosely structured rhetorical situation:

> Situations may become weakened in structure due to complexity or disconnectedness. A list of causes includes these: (a) a single situation may involve numerous exigencies; (b) exigencies in the same situation may be incompatible; (c) two or more rhetorical simultaneous rhetorical situations may compete for our attention […] (p. 12)

Wikipedia is unique in that it requires potential rhetors to collaborate not only to create content but also to manage the many coordination tasks necessary for collaboration, including mediating conflict. While different Wikipedians take on different kinds of work (e.g., serving as an administrator, addressing copyright violations, creating templates, resolving disputes), the design of the system often makes it difficult for a single editor to create content without the pressure of responding to numerous, simultaneous, and incompatible exigencies at once. I say more about this below.

Audience

According to Bitzer (1992), the *audience* of any rhetorical situation "consists only of those persons who are capable of being influenced by discourse and of being mediators of change" (p. 7). We can interpret this narrowly to mean "other editors" or we can interpret this more broadly to mean "everyone." If we use the latter interpretation, we can think of women who read health information on Wikipedia as "capable of being influenced." Certainly, the editor who advocated for the creation of WP WH envisioned the audience for women's health articles as "women interested in their own health":

> Women's health articles need a lot of improvement. Many of them are outdated or overly jargony [*sic*]. They tend to be written for medical professionals and researchers and often have little or no practical information for women interested in their own health. This project would compliment [*sic*] the WikiProjects listed above by improving and expanding these articles, including adding information of practical value to women, and addressing social and political topics related to women's health.

The findings above, however, indicate that not all of the WP WH members agree with his understanding of audience and that some may even vehemently disagree with adding "information of practical value to women" to medical articles. The problem, of course, is that any rhetorical situation—despite Bitzer's circumscribed definition—can consist of both intended and unintended audiences, particularly when it comes to digital media. In reality, women seeking health information, people who may learn about and/or be impacted by a woman's health event, medical students and/or medical practitioners, and high school students presumed to have limited access to information sources are *all* potential audiences for women's health content. Of course, so are reporters, researchers, and search engine algorithms. This kind of diffuse and shifting audience makes creating women's health content on Wikipedia even more challenging, particularly as WP WH does not have a Manual of Style (Mos). Interestingly, WP Medicine does have a MoS, and it is very clear about who the audience should be for medical content on Wikipedia:

> Wikipedia is written for the general reader. It is an encyclopedia, not a comprehensive medical or pharmaceutical resource, nor a first-aid (how-to) manual. Although healthcare professionals and patients may find much of interest, these two groups do not by themselves represent the target audience.[46]

Envisioning the audience as “the general reader” assumes there can be a “general reader”: a reader unfettered by embodiment and lived experiences, by medical conditions, by gender. This phrase hints at Wikipedia’s underlying post-positivist epistemology; the identity of the knower and the context in which knowledge is produced and disseminated are irrelevant (e.g., Wray, 2009; Gruwell, 2015). However, participants disagree with this conception of the reader—from Sara who cares that medically accurate information is delivered in an emotionally sensitive way to Eileen who imagines she has received a diagnosis when writing about it to Henry who thinks about how information about burns may be more relevant to women’s health in certain parts of the world. There are growing cracks between how Wikipedia (wikipedia.org) envisions its audience as evidenced by its policies and guidelines and how editors envision their audiences. These cracks make me hopeful.

Constraints

> There has been a disappointing dearth of encyclopedias from a feminist point of view, but recent work on feminist epistemology suggests that such an undertaking would reinvigorate the often stuffy world of reference work.
>
> Andrew Brown, 2011

Finally, any given rhetorical situation can have multiple constraints; Bitzer includes things like “beliefs, attitudes, documents, facts, traditions, images, interests, motives, and the like” (p. 8). If we consider Bitzer’s list, Wikipedia has many, many constraints, but I want to touch on two that are essential to how women’s health content is created on Wikipedia: *the genre of the encyclopedia* and *the culture of Wikipedia*.

Though Bitzer does not address genre in his essay and may not have considered genre a constraint (but rather a response to a rhetorical situation), I would argue that because Wikipedia conceptualizes itself as an encyclopedia, *genre functions as an antecedent constraint*. The encyclopedic genre is one with very specific epistemological concerns: “Encyclopedias are in the business of transmitting information and knowledge from one group of people to another group of people. In other words, their goal is to disseminate existing knowledge rather than to discover new knowledge” (Fallis, 2008, p. 1663). This genre-specific constraint is why Wikipedia restricts the kinds of sources editors can use and has a policy about not citing original research. During conversations with Henry, for example, he often pointed to WP Medicine’s MoS and stressed editors working on updating medical content most often rely on metareviews. This may be why, as Matthew observed, Wikipedia does not have an article about period tracking apps (though an article about *femtech* and articles for specific apps such as Clue and Flo were created within the last month). When I asked Henry about this topic specifically, he said “So, right now what we’re seeing is very early evidence on these apps. With respect to the quality of evidence that’s available, it might be worth mentioning it in the research section [of the *Birth control* article].” In this way, Maher is correct: Wikipedia mirrors the world’s biases because the genre of the encyclopedia dictates that disseminating existing knowledge is one of its primary constraints. As noted in Chapter 2, we know that research about women’s health is underfunded and, often times, highly politicized.

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[46] See https://en.wikipedia.org/wiki/Wikipedia:Manual_of_Style/Medicine-related_articles#Writing_for_the_wrong_audience

Furthermore, since the first known encyclopedia authored solely by Pliny the Elder (Brown, 2011), encyclopedias have become sites of *social knowledge production* rather than individual knowledge production and, thus, rely on *the epistemology of testimony*. That is, how can one know something just because someone else says it is so? In the case of Wikipedia, some (e.g., Fallis, 2008) have argued that the testimony of Wikipedia (and, implicitly, Wikipedians via *group testimony*; Tollefsen, 2009) is accurate, reliable, and verifiable due to the "wisdom of the crowds," Wikipedia's infrastructure, and its policies. These arguments are naïve, both in their understanding of Wikipedia and encyclopedias generally. Although Wikipedia (and the hundreds of encyclopedias that predate it) is authored by multiple contributors, that does not mean it is not united by an editorial perspective or an underlying epistemology. In fact, the genre of the encyclopedia has historically been motivated by specific political aims, such as classifying the colonized world or cultivating civil servants in China (Sullivan, 1990). These often-unarticulated political aims and biases have resulted in both racist and sexist paper-based encyclopedias for both children and adults as recently as the early 1980s (Sloan, 1970; Kraft, 1973; Engle & Futas, 1983). This leads to my second point.

The *culture of Wikipedia* is yet another constraint specific of the online encyclopedia. Bitzer writes that reoccurring rhetorical situations can establish a precedent: "The situation recurs and, because we experience situations and the rhetorical responses to them, a form of discourse is not only established but comes to have a power of its own—the tradition itself tends to function as a constraint upon any new response in the form" (p. 13). As other researchers have noted (e.g., Reagle, 2013; Eckert & Steiner, 2013; Gruwell, 2015), the belittling and hostile discourse of Wikipedia has become so deeply embedded in the culture of Wikipedia—including its policies, guidelines, and norms—that the community has developed neologisms like "Wikilawyering"[47] and guidelines like "Don't be a dick" (redirected in 2014 to "Don't be a jerk"[48]). This may explain why women's health information that is stigmatized (i.e., information about an intact dilation extraction (IDX) procedure, as Sara noted) and/or about emotions is much more likely to be contested.

The design of Wikipedia

In several instances, participants alluded to how the design of Wikipedia made it more difficult for WP WH to succeed despite the project's use of WikiProject X. In my own experience, because the link to the archived project talk pages had not yet been created, I spent more time than I would like to admit fruitlessly searching for archives before Matthew helped me. Below, I discuss specific barriers and related opportunities for design interventions related to creating women's health content on Wikipedia.

Barriers

The current design of Wikipedia presents several barriers to those who may want to become involved in WP WH and/or create women's health content. First, WikiProjects are difficult to discover. As Kate and William shared, they only stumbled across WikiProject templates in the process of editing articles like *Breast hypertrophy*. That is, they had to be engaged in active editing to discover WP WH. Second, even with the semi-automated maintenance provided WikiProject X, the findings above support prior research that finds the momentum of a project is difficult to maintain without a "critical mass," and early

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[47] See https://en.wikipedia.org/wiki/Wikipedia:Wikilawyering

[48] See https://meta.wikimedia.org/wiki/Don%27t_be_a_jerk

contributions of “power users” may actually stall rather than bolster a WikiProject (Solomon & Walsh, 2014). In the case of WP WH, the founders of and earliest contributors to the project were all highly experienced and prolific editors—many of whom held positions of leadership either within the community (i.e., administrator, Arbitration Committee member) or with the Foundation (i.e., employee, Wikipedian in Residence, board member). As Navi recounted, “I signed up because everybody signed up, and I was very interested in the cause. But I did not have sufficient time and resources for propelling the project forward […]”. WP WH, then, might benefit from increased discoverability, particularly among new editors who have more time to devote to creating women’s health content.

Related to this point is that a new editor to Wikipedia who does discover WP WH may have a difficult time uncovering the scope of the project and the ways in which the members have defined women’s health. As noted above, competing exigencies and an ambiguous notion of audience can make creating women’s health content on Wikipedia more difficult, even for experienced editors. A new editor is unlikely to read dozens of conversations across article talk pages, project talk pages, and project proposal pages to understand the lay of the land before editing.

Finally, Wikipedia’s dependence on Commons—and the design of Commons itself—presents specific barriers to illustrating women’s health content on the site. When asked what they thought was missing from women’s health content on Wikipedia, participants consistently replied, “Images.” However, Commons does not currently offer a collection of appropriate images for women’s health that, as Whitney said, “reflect the reality of most of the world.” Even if one is able to attain a high-quality medical image and the appropriate consent from all of individuals and institutions involved, the process of uploading and licensing an image is confusing and may involve personal and professional risks.

Opportunities

Of course, these barriers present several opportunities for design interventions. As my colleagues and I argue in a study about participation in Commons (Menking, Rangarajan & Gilbert, 2018), re-defining participation by broadening the ways in which someone can contribute may increase participation and diversify the contributor base. For example, introducing interventions that allow “lightweight” participation (Haythornthwaite, 2009) and evidence awareness of users’ desires. One can image a design intervention (similar to what Gilbert et al., 2013 suggest, but simplified and for readers rather than researchers) that allows readers of women’s health articles to rate the accuracy, completeness, helpfulness, and/or readability of an article—perhaps even annotating specific passages—without clicking “Edit” or posting to an article talk page. This data could then be aggregated with already available information (e.g., page views) to help editors prioritize their work.

As my colleagues and I found in our study of Commons (Menking, Rangarajan & Gilbert, 2018), a lack of awareness is a major factor that contributes to a lack of participation; Shaw & Hargittai (2018) argue the same in their work about the “pipeline” of participation and Wikipedia. While there have been efforts to improve the on-boarding experiences of new users to Wikipedia (e.g., tools like Snuggle, spaces like The Teahouse, or gamified tutorials like The Wikipedia Adventure), these interventions have not proven successful in increasing newcomers’ participation (Halfaker et al., 2014; Narayan et al., 2017). These unsuccessful interventions may be because these attempts to increase awareness and on-board new users have all been designed and developed by Wikipedians. I would argue that participatory design research *led by* non-Wikipedians might prove more useful in the future.

Editors' beliefs about gender *vs.* editors' gender identities

Finally, though I did not set out to elicit participants' beliefs about gender, many shared their opinions, stories, and experiences of Wikipedia's gender gap as well as their thoughts about gender and gendered relationships in general.[49] For example, William told me he is as a feminist and has spent his career advocating for gender equality. Based on the empirical evidence above and my five years of experience as an active member-researcher in the community, I would argue that an editor's beliefs about gender and gendered relationships—versus an editor's gender identity alone—may be a more relevant factor to consider when interrogating the relationship between the participatory gender gap and related content gaps. This is not to say that an editor's embodied experiences as a gendered individual are not important; clearly, the women I interviewed expressed their positionality as cisgender women as motivating aspects of their contributions. But, as we know, women can also perpetuate sexism, patriarchy, and even misogyny (e.g., Glick & Fiske, 1997; Fischer, 2006; Szymanski et al., 2009; Enloe, 2017). A more predictive measure of what and how someone may edit—regardless of their gender identity—may be how they answer the prompt, "Tell me what you think about gender."

This deceptively simplistic rhetorical turn has very real implications. For example, as some women Wikipedians have noted, recruiting more women is not the answer (Wadewitz, 2013); in fact, efforts to "add more women and stir" are not only reductive, they are also problematic because they reinforce sexist and binary assumptions about what women may be interested in and about gender more broadly. Moreover, research studies that make these assumptions—conflating binary gender demographic data points with content gaps—are also problematic and, I would argue, dangerous insofar as their ability to reinforce sexist and binary assumptions about gender. However, many previous, frequently cited studies (see Appendix A) have assumed that the participatory gender gap is responsible for the lack of coverage and quality of content presumed to be of interest to women. I made this mistake myself when I first began researching women and Wikipedia.

Limitations

As an exploratory study, this work has specific limitations. For example, as mentioned above, the sample size was small. I spoke to only eight explicit project members; moreover, I did not interview editors who contribute to women's health content but who do not belong to WP WH. Additionally, I focused only on the English language Wikipedia, which—though the largest and oldest of all language Wikipedias—is only one of more than 300 Wikipedias. Finally, I did not interview Wikipedia readers, so I cannot speak to their perspectives of and experiences with women's health information and WikiProject Women's Health on the English language Wikipedia. Despite these limitations, the findings above provide a strong empirical foundation for future work about women's health content on Wikipedia and the relationships between participatory gaps and content gaps. For example, the question of how women's health content is illustrated and, relatedly, Wikipedia's dependence upon Wikimedia Commons deserves an in-depth study.

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[49] Interviewees may have talked to me about the gender gap because of my previous work, reputation in the community, gender identity, or focus on women's health information.

Conclusion

In many ways, this study about WikiProject Women's Health and creating women's health content on the English language Wikipedia became unwieldy. While my findings provided descriptive answers to my research questions, they also prompted many more questions than they answered. Some of the questions we might ask based on the findings in this chapter include: If some content in a UGC system is more difficult to create (i.e., medical content), how might we design the system (e.g., user interfaces, tools, processes, policies) to reduce barriers to contributing? Who is the audience for Wikipedia's women's health information? Who decides who the audience is? How might perceptions of "competence" and expertise be gendered on Wikipedia? How might embodiment and lived experiences motivate and impact the ways in which editors contribute to the site?

In writing this chapter, I learned that creating women's health content on the English language Wikipedia requires overcoming more than the already notable barriers (e.g., digital access, literacy, awareness) to click "Edit." One must also have a certain amount of domain-specific expertise or—at least—the ability to access, read, interpret, and summarize medical sources (what Wikipedia calls "competence"); the ability to navigate Wikipedia, the system (e.g., different namespaces, tools and features); the ability to engage with and understand the Wikipedia community, including its many policies, guidelines, and essays as well as its unwritten rules (see Chapter 3); and the social, material, and emotional capital required to perform unpaid labor that is often taxing and results in burnout. In short, the people who create women's health content on Wikipedia are, according to Ericsson & Smith's definition, *outstanding* (Ericsson & Smith, 1991; see Chapter 2 for my operationalization of expertise). Are there more "outstanding" men than women in the world? That is, are there more men with expertise about women's health? Is that why it took 14 years to create WikiProject Women's Health? Is that why it is so difficult to illustrate women's anatomy and health articles or find sources to cite about alternative approaches to women's health? Does it really come down to a lack of women? No, not according to the data in this study. The women I interviewed outnumber the men (this could, of course, be due to self-selection bias), and the majority are also outstanding in the ways they have navigated patriarchal systems both in the United States and abroad to secure advanced degrees and economic security. They are also, as noted above, relatively privileged (e.g., benefit from whiteness or belonging to a certain socioeconomic class).

If we want to understand what contributes to content gaps assumed to be gendered, then we need to attend not only to gender as a demographic data point but also to how people think about gender and gendered relationships as well as how *intersectionality* impacts who edits Wikipedia. We need to ask why the majority of men editing Wikipedia's medical content do not edit women's health content. We need to ask if the majority of women who edit women's health content on Wikipedia are white and well-educated. We need to ask in what ways sociotechnical systems like Wikipedia are designed to valorize certain kinds of behaviors and prioritize certain kinds of knowledge. Wikipedia is a particularly interesting and useful site of study because we can *see* how knowledge production takes place and is continuously negotiated. Does it, as Maher claimed in her 2018 Op-Ed, only mirror the world's biases, or does it also magnify them? I turn to this question in Chapter 6.

Chapter 6: Using Object Biographies to Understand the Production and Neglect of Women's Health Content

Introduction

When I began my research about Wikipedia's participatory gender gap in 2013, one of the first things I did was subscribe to the Gendergap mailing list, a publicly archived email list provided by the Wikimedia Foundation "to collectively address the realities of the gender gap."[50] Looking at the archive then, I noticed the list had been established in 2011 but that use had begun to dwindle just before I joined. By 2016, I received email digests so infrequently that I had forgotten about the list altogether. However, in October 2017 a request for "more women's voices" in an on-Wiki discussion about whether a video should be removed from the *Abortion* article initiated a flurry of messages. After editors reached a consensus to delete the video, an administrator closed the on-Wiki discussion, but the email thread continued for several days:

> […] If obstetrics is being described in terms of storks (what, no cabbage patch?) then pediatrics on Wikipedia is even more dismal. I wondered about this article on infant sleep training and why it is assigned to women's health project. Does Wikipedia recognize no difference between gynecology and pediatrics?
>
> Yeah, if you wanted a case study of what implicit bias looks like, just look at health care. […]
>
> Most health articles on Wikipedia are about men's health. I think you will find lots of stuff still covered by good 'ol 1911 Encyclopedia Britannica. […]

The comments above—excerpts from three messages, each posted by a different editor—piqued my interest. As I read through the thread, I reflected on the interview data I had gathered between 2016 and 2017. Participants, editors who contributed to a range of medical and health related articles, including women's health content, disagreed with the editors on the Gendergap mailing list and with each other. For example, Henry, began one of our conversations with the following remark:

> *There's sort of this hypothesis bandied around that Wikipedia's coverage of women's health is likely worse than Wikipedia's coverage, let's say, of men's health. I've heard that a number of times. I've never seen anybody come forth with any evidence to support that. My personal experience is that that's wrong. I think our coverage of women's health is at least as good if not better than our coverage of men's health.*

But when I asked Sara what kinds of information about women's health were missing, she replied: "Everything! All of it! Oh my god, there's so much, it hurts." Similarly, Whitney said:

> *Whenever I first got involved working with medical stuff again, which was about two and a half years ago, I went through and looked at some of the articles related to OB-GYN information, and I found something that had to do with psychosis during pregnancy, and it was one of the most embarrassing articles I could have ever seen in my entire life. It was written from case studies from the 1800s, and it was talking about women being hysterical with case studies, okay? I actually took out large swaths of the article, and I eventually put it up to be merged. I merged it*

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[50] See https://lists.wikimedia.org/mailman/listinfo/gendergap

> *into something else and made it go away completely because it was so embarrassing. And I thought, "How many times had people who are in medicine and working on medicine seen that article and just not done anything about it?" Knowing how awful it was, you know what I mean? That's the part that kind of gets me. It just isn't important, I guess.*

So, who was right about women's health information on Wikipedia? Whitney and Sara? The editors commenting on the Gendergap mailing list? Henry? What was the current state of women's health information on Wikipedia? Where was the evidence? What did it say?

As I began to ask these questions, I realized interview data alone was not sufficient to answer them. While I wanted to know how editors perceived the breadth, depth, and quality of women's health information on Wikipedia, I also wanted to know what the articles themselves had say. Given prior work by Geiger & Ribes (2010; 2011) in which they introduce "trace ethnography" and use digital traces to study the blocking of a Wikipedia vandal and Wyatt, Harris & Kelly's (2016) study in which they perform thematic analysis of "collected material including words, images and hyperlinks" (p. 17) to interrogate controversy about schizophrenia genetics on Wikipedia, I decided to adapt the method of *object biography*—a material culture practice used in anthropology—to reconstruct the life-history of a selection of women's health articles. Drawing from article revision histories, talk page discussions, trace data, interviews with editors, and five years of ethnographic research, I wrote a biography for five articles, noting how they have grown, been neglected, become boundary objects for different communities (e.g., editors, readers, corporations, medical practitioners, laypeople), sparked debates about how scientific knowledge is reproduced, and complicated assumptions about the relationships between participation and content in user-generated content (UGC) systems.

In this chapter, I present three of these object biographies and ask: *How can we use object biography to understand the production and neglect of women's health information in sociotechnical systems like Wikipedia?*

Related Work

This chapter sits at the intersection of related work about attention, maintenance, repair, and care, and neglect. Below, I briefly review selected studies, focusing primarily on directly relevant literature from anthropology, STS, CSCW, and HCI. (For a discussion of women's health in general and women's health information online, see Chapter 2; for a description of Wikipedia as a site of study, see Chapter 3.)

Attention

A few years ago, Nick Seaver, an Assistant Professor of Anthropology at Tufts University, began teaching an advanced seminar about "attention as a cultural phenomenon" (Schwartz, 2014). The course, entitled "How to Pay Attention," includes the following description in its syllabus:

> This course is an advanced seminar in the anthropology of attention. What makes the anthropology of attention different from other ways of studying attention (e.g. psychology) is that we study it as a *social* and *cultural* phenomenon: attention is not just a matter of individual minds selecting objects from environments. Rather, attention is collectively organized and valued. We learn how to pay attention and what to pay attention to from other people; other

> people make technological and media systems to intentionally organize collective attention. We learn to value certain kinds of attention (e.g. intense focus on work, mindfulness, or multi-tasking) and to criticize others (e.g. absent-mindedness, distraction, intense focus on entertainment) in cultural contexts. So, while we will be experimenting with our own attentions throughout this course, we will remember that our attentions are not really our own. No one pays attention alone.[51]

Like Seaver, other scholars (e.g., Simon, 1969; Goldhaber, 1992, 1997, 2006; Davenport & Beck, 2001; Crogan & Kinsley, 2012; Tufekci, 2013) have also written about what is now called "attention economics"; however, Seaver's approach differs in that he is focused on studying *collective* attention as a cultural phenomenon. Of direct relevance to this chapter and the object biographies herein is his statement that "other people make technological and media systems to intentionally organize collective attention." As I tell the following life-histories of three Wikipedia articles about women's health, I ask how the system has been designed to direct editors' collective attention.

Maintenance, repair, and care

Maintenance and repair have received an increasing amount of attention from CSCW, HCI, and STS scholars in recent years. From Steve Jackson's chapter "Rethinking Repair" (2014) to the establishment of The Maintainers, "a global research network interested in the concepts of maintenance, infrastructure, repair, and the myriad forms of labor and expertise that sustain our human-built world,"[52] much of the conversation draws on earlier work by feminist scholars like Gilligan (1982), Suchman (1995, 1996, 2007), Tronto (1993), Puig de la Bellacasa (2011), and Star (Star & Strauss, 1998; Star, 1999). At times implicit and, at times, explicit in recent work about maintenance and repair is also the notion of *care* (e.g., Light & Akama, 2014; Toombs et al., 2017). For the purposes of this chapter, I draw on Puig de la Bellacasa's (2011) "matters of care" (an extension and critique of Latour's "matters of concern") in which she describes care as "both a doing and ethico-political commitment that affects the way we produce knowledge about things" (p. 100). In particular, I am interested in how we care (or do not care) for neglected things (such as women's health articles on Wikipedia) and attend to the relationships between these things and other things, including human and non-human agents.

Neglect

Writing about the risks of neglecting infrastructure, Horning & Neumann (2008) observe, "Neglect is the inertially easy path" (p. 112). In fact, the word *neglect*, which originated in the early 16th century from the Latin verb *neglegere*, is a combination of *neg* (not) and *legere* (choose, pick up). While *neglect* today generally refers to the failure to perform a duty—such as caring for a child—the origins of the word point to another meaning: *not to choose*, or *not to pick up*. Neglect is, in both cases, tied to attention and care. Neglect *is* the inertially easy path in that it requires a non-choice. As Whitney said:

> *And then we just have the neglected articles that someone wrote at some point and didn't get very far with them, and they abandoned them. And they're [the articles] outdated or stale, and not really very good to start with. They're start articles. And, you know, we have content like that in women's health—a good bit of it. So, I think that that is discouraging.*

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[51] See http://nickseaver.net

[52] See http://themaintainers.org

As Whitney notes, abandonment is also tied to attention and priority, but it assumes an initial foundation—something that has once been cared for and was once in good repair that has since been left to fall. In the case of women's health information on the English language Wikipedia, both neglect and abandonment apply. It could also be argued that neglect and abandonment have something to do with power. The one capable of enacting care—of devoting time and attention—is in a position of power and has more agency than the person or thing being cared for. I return to this idea in the object biographies and Discussion section below.

Object Biography

To write an object biography, one must *attend* to the thing. An object biography requires attention, care, and curation, which results in a specific kind of knowledge production: a new understanding of a familiar thing. Here, I adapt object biography to interrogate specific Wikipedia articles, which to the best of my knowledge has not been done. To read more about the method of object biography, please see Chapter 4.

Methods

Ethical considerations

I obtained Institutional Review Board (IRB) approval from the University of Washington before recruiting interviewees for this study. I provided all interviewees with study information and asked they (1) acknowledge they were 18 years of age or older and (2) provide either verbal or written consent. I offered interviewees compensation in the form of Amazon gift cards ($25 per physical card) funded by the University of Washington Information School's doctoral dissertation grant. For additional information about the ethical considerations of this study, please see Chapter 4.

Sampling

To select articles for object biographies, I used Trost's (1986) approach to statistically non-representative stratified sampling. Trost recommends listing independent variables relevant to the purpose of the study which can then be dichotomized or trichotomized (p. 55). I considered three variables when selecting object biography candidates: (1) whether an article discussed a condition, illness, or disease pertaining to sexual and reproductive health or non-reproductive health, (2) the prevalence rate of said condition, illness, or disease, and (3) the associated stigma. See Table 1.6. For more information about sampling, please see Chapter 4.

Table 1.6. Potential article candidates for object biography selected using Trost's sampling method (1986). As Trost notes, some cells may be logically or empirically empty (p. 55). For example, when I collected my data, I could not find a B or C class article about a reproductive and/or sexual health issue that was both rare and relatively low stigma.

Reproductive & Sexual Health												
Stigma	Low						High					
Prevalence	Rare			Common			Rare			Common		
Quality	Low	Mid	High	Low	Mid	High	Low	Mid	High	Low	Mid	High
Article	*Acute fatty liver of pregnancy*		*Coffin birth*	*Atrophic vaginitis*	*Menstruation*	*Birth control*	*Vaginal cancer*	*Endometriosis*	*Abortion–breast cancer hypothesis*	*Abortifacient*	*Human papillomavirus infection*	*HIV/AIDS*
Non-Reproductive Health												
Stigma	Low						High					
Prevalence	Rare			Common			Rare			Common		
Quality	Low	Mid	High	Low	Mid	High	Low	Mid	High	Low	Mid	High
Article		*Turner syndrome*		*Thyroid disease in women*	*Breast cancer*	*Migraine*	*Morgellons*	*Eating disorder*			*Violence against women*	*Major depressive disorder*

Between June 2016 and January 2018, I also conducted 15 semi-structured interviews with 14 Wikipedians who are either members of WikiProject Women's Health and/or have made significant contributions to specific women's health articles included in the sample (Table 1.6). I used purposive sampling to recruit interviewees, contacting prospective participants through Wikipedia email. I avoided using You've Got Mail (YGM) notifications on editor's talk pages because I did not want to compromise their confidentiality. I copied myself on all emails, using my University of Washington email address. In total, I contacted 26 editors; 17 replied and 14 consented to interviews.

Data collection

For each article, I collected article revision histories, talk page discussions, and trace data. To do this, I used a Python script to scrape Wikipedia, collecting all revisions and logs for each article to create two CSV files per article: revision data and log data. I also manually inspected each revision for each article and took screenshots of versions that evidenced significant content change (i.e., the inclusion of a new paragraph), introduced new references or resources, or images. I read all talk page discussions, took screenshots of page information data, and downloaded page view data. I also added each article page to my watchlist, a page that allows users who are logged in to receive notifications when changes are made to selected article pages and their associated talk pages.

I conducted all interviews in English via telephony applications (e.g., Skype, Google Hangouts) or phone. With participants' permission, I audio-recorded the interviews and took handwritten notes. Interviews ranged in duration from 30 minutes to more than two hours. I interviewed one editor twice as he is a WikiProject Women’s Health member and has also contributed significant content to three of the articles identified in Table 1.6. I had previously interviewed three of the editors in past work about women and Wikipedia, and I had previously met four of the editors in person at either Wikimania, the annual conference for the Wikimedia communities, or local edit-a-thons.

Data analysis

All article data was analyzed in a non-linear and iterative fashion. For example, as I coded the log and revision data I downloaded into CSV files, noting different kinds of edits, including acts of vandalism (VAN) and subsequent reversions (REVERT), applications of categories (CAT) and tags (TAG), and content creation (CC), I also manually inspected revision histories on Wikipedia. During this time, I was also conducting axial coding of a subset of interview data and writing memos to identify emerging themes.

I transcribed all audio-recordings verbatim with the exception of one (Carolyn) because the audio-recording failed. (I took notes during and immediately following the interview and then sent these to her for review). After transcribing the audio-recordings, I imported all interview transcripts and interview notes into NVivo, a qualitative data analysis software tool, where I then conducted *in vivo* coding (Manning, 2017). Because the interview data was collected iteratively and in tandem with other data (e.g., article and talk page data, trace data), I used open coding and memoing to identify emerging themes across data sources (e.g., Miles & Huberman, 1984; Strauss & Corbin, 1998). As I identified these themes, I altered the interview protocol. Finally, I conducted axial coding of a subset of interview data (Table 2.6).

*Table 2.6. Demographic information for interviewees whose data was included in axial coding. * Number of years editing the English language Wikipedia as of date of interview, determined by self-reported data and trace data from Wikipedia. Note: I interviewed Henry twice.*

Pseudonym	**Gender**	**Formal medical training?**	**Years on EN***
Carolyn	Woman	N	11
Eileen	Woman	N	11
Henry	Man	Y	11
Kate	Woman	Y	2
Navi	Woman	Y	8
Sara	Woman	Y	11
Shanna	Woman	N	13
Simon	Man	Y	12
Whitney	Woman	Y	13
William	Man	Y	12

Findings

In the sections below, I tell the life-history of each of the following three articles: *Atrophic vaginitis*, *Vaginal cancer*, and *Women's health*. I have chosen these three articles because, in the course of interviewing editors, I drew their attention to the ways in which these specific articles had been neglected and, in doing so, I inadvertently shaped the articles' life-histories. In telling these life-histories, I ask: *What is the article? What does it do? When did it come into being? How? Who was involved in creating it? Who maintains it? What kinds of relationships does it have with other articles? With other parts of Wikipedia? With other kinds of online information about women's health? With editors? What do they want it to be? What does it want to be?*

I have organized the first two object biographies to reflect one of my arguments which I expand on in the Discussion section: health content that disproportionately impacts women with intersecting identities may be more likely to be neglected.

Atrophic vaginitis

Before I began this study, I did not know what atrophic vaginitis was. As a healthy, premenopausal cisgender woman who has never smoked, had a child, been diagnosed with diabetes, or had chemotherapy, why would I? It is a condition outside of my lived experiences, my daily worlds, my attention. However, given the prevalence of atrophic vaginitis, I am likely to care about it one day: "Vaginal dryness and atrophy is a silent epidemic that affects many women who are undoubtedly suffering in silence. This chronic and progressive medical condition has been estimated to affect up to 50%-60% of postmenopausal women" (Krychman, 2007). Why is atrophic vaginitis a "silent epidemic"? Why have the older women in my life never told me about it? Why—to quote Eileen—are there "all these little back alleys of things that are missing [on Wikipedia], especially for older women"?

> *For example, at this present time, I'm helping to improve the [title] article. And what you said about Atrophic vaginitis, that you just mentioned? Well, that's not in the [title] article. What I have to do—well, in my mind, anyway—I have to go back and bring the Atrophic vaginitis up to speed, and then I can enter the information in the [title] article. So, there's all these little back alleys of things that are missing, especially for older women, and you just nailed that one article right there.*

In the following section, I examine the *Atrophic vaginitis* article to tell its life-history—in the context of Wikipedia, other information sources, women's experiences, and the condition itself—and to understand how stigma (e.g., gender-related, age-related, and sex-related) and participatory gaps (e.g., age and gender gaps) may interact with women's health content on Wikipedia. I present this object biography of the article—now 13 years old—as a series of vignettes, beginning with the birth of the article and the first decade of its life.

The birth of an article

In April 2006, a user (hereafter referred to as Editor 1) created the *Atrophic vaginitis* article with the following definition:

> Medical term: atrophic vaginitis.

> An inflammation of the lubricated inner lining of the vagina that is caused by thininng [*sic*] and decreased vaginal lubrication. The most common cause is the decrease in estrogen after menopause; although, it can be caused by other conditions such as those requiring treatment with anti-estrogen drugs. Symptoms include vaginal soreness and/ or itching, painful intercourse, and sometimes bleeding after sexual intercourse. Treatment typically consists of topical estrogen cream and/ or oral estrogen replacement.

Less than an hour later, Editor 1 removed *Medical term: atrophic vaginitis* and replaced it with *Also known as: vaginal atrophy*. Two days later, Editor 1 changed the redirect from *Vaginal atrophy* to *Vaginitis* so that the redirect linked to *Atrophic vaginitis* instead. Editor 1 never edited Wikipedia again.[53]

The first decade of life

During the first year of the article's life, it was edited 24 times, including Editor 1's initial two edits. Eleven edits were made by a single editor (Editor 2) in September 2006. These edits resulted in a fairly substantial re-write with the addition of sections (e.g., "Signs and Symptoms," "Diagnosis," "Treatment"), and a boxed warning about estrogen-only treatments.

Two interesting changes were made to the *Atrophic vaginitis* article during this time that may imply certain assumptions about the topic or about women's health overall. First, Editor 2 made a puzzling inclusion of the category "Menstruation" to the article. Second, prior to Editor 2's work, another editor changed the template for the *Atrophic vaginitis* article from the original medical stub article template to the template for a disease stub article. However, atrophic vaginitis is neither associated with menstruation nor is it a disease. These edits reflect what Wikipedians call good faith edits, or "the assumption that editors' edits and comments are made in good faith." Here, "good faith" is hyperlinked to the Wikipedia article of the same name, which begins, "Good faith (Latin: bona fides), in human interactions, is a sincere intention to be fair, open, and honest, regardless of the outcome of the interaction." But what these "good faith" edits may signal is that, at least early in Wikipedia's history, either editors did not expect one another to know a lot about women's health and/or no one was carefully monitoring women's health articles. For example, if we compare the early history of *Atrophic vaginitis* with the case made against Editor 0 in which she was banned for not evidencing the appropriate amount of competence (see Chapter 5), we see a noticeable difference in how much attention "good faith" edits to women's health articles received a decade ago.

In contrast, the rest of 2006 was marked by *bad faith edits* and subsequent bot maintenance. For example, an unregistered IP address blanked the article twice, replacing all of the text with: "i love 'penis' between my buttcheeks." Bots quickly reverted these acts of vandalism, and the article passed into its second year of life to see more vandalism and subsequent reversions.[54]

At the end of the first decade of the article's life, a new editor (Editor 3) who, according to their user page, was interested in writing about "laser & medicine," added a significant amount of text and several references about "fractional CO2 laser therapy" as a possible treatment, detailing the role of "an Italian Laser Company." These edits were reverted within seconds by a bot, ClueBot NG, because they were

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[53] To be more accurate, Editor 1's account has not been used again. The user who was using Editor 1's account *may* have edited again, but they did not use this account.

[54] Although vandalism is prevalent on Wikipedia, articles about women's anatomy and health *may* be more frequently vandalized given the topical content and given the articles are rarely protected; this would make a fascinating study.

promotional. Aside from adding citations to two other articles and editing their user page (for a lifetime total of nine edits), Editor 3 never edited Wikipedia again.

Between 2006 and 2017, the article was edited 99 times (on average, only nine edits per year; in comparison, *Testicular atrophy* was created in 2004 and by 2019 has been edited only 112 times whereas *Erectile dysfunction* was created in 2001 and by 2019 has been edited 2,114 times). (See Table 3.6.) By 2016, the *Atrophic vaginitis* article had grown to include two outdated references (not counting the references added by Editor 3 and subsequently deleted by ClueBot NG): a 2000 article from *American Family Physician* and a 1991 piece from a German publication that translates to *Gynecological-Obstetric Review*. According to Google Scholar, between 2006-2016, more than 5,000 studies about atrophic vaginitis were published; according to PubMed, between these same dates, 111 studies related to atrophic vaginitis were published. Thus, there were more recent sources available to be cited.

Table 3.6. A comparison of six articles including birth date of article, lifetime edits as of July 2019, size in bytes as of July 2019, and the number of original article talk page posts (not including replies) as of July 2019. Note that, with the exception of Testicular atrophy, the example articles related to women's reproductive health evidence fewer edits and discussion and are smaller in size. Also note that both Atrophic vaginitis and Vaginal cancer were created 2-5 years after the four articles related to men's reproductive health.

Article with birth year	**Lifetime edits**	**Size (in bytes)**	**Talk page posts**
Testicular atrophy (b. 2004)	112	5,367	2
Atrophic vaginitis (b. 2006)	192	11,801	4
Vaginal cancer (b. 2007)	243	14,192	2
Penile cancer (b. 2003)	536	19,090	13
Testicular cancer (b. 2003)	2,096	45,090	21
Erectile dysfunction (b.2001)	2,115	34,003	45

"Reduced enjoyment"

In 2012, the *New York Times* ran a "Personal Health" column in which Jane E. Brody discussed treating sexual pain:

> Millions of women experience vaginal discomfort, and sometimes crippling pain, for a variety of reasons, most often a loss of estrogen. The resulting vaginal dryness and atrophy can make sexual intercourse, a pelvic exam, urinating, or even sitting, walking or cycling a painful nightmare.

Although doctors frequently disbelieve women's reports of pain and may discredit this "painful nightmare" (see Chapter 2), alternative health practitioners, celebrities, spas, and companies that produce feminine hygiene products have stepped in to fill the void (e.g., Weiss, 2017; Cohut, 2019; Prinzivalli, 2019). From probiotics to vaginal douches to cannabis suppositories to jade eggs to vaginal steams, the market certainly recognizes the emotional and psychological impacts of atrophic vaginitis in women's lives and is prepared to profit in the process.[55] (I return to this phenomenon below.) However, on Wikipedia, the *Atrophic vaginitis* article concedes to the painful reality of the condition in only one sentence: "Women often report reduced enjoyment in sex as well as life generally."

When I spoke to women editors about women's health information on Wikipedia (see Chapter 5), they consistently expressed frustration with other editors—primarily men who are medical practitioners—who refuse to include information about the psychological and emotional impacts of women's health issues. For example, Eileen talked about the work she had done on the *Miscarriage* article:

> *There was a section that I thought was missing, and it had to do with the psychological and emotional effects of miscarriage, and I created a whole other article based upon that because, well, the other editors—I should say editor—didn't think it was significant and wanted to cover it in two sentences.*

Sara reported similar interactions on the same article:

> *So, I got into a fight with him over the Miscarriage article [...] we had this long fight about where to put the emotional [qualities] of miscarriage, and I thought it was really inappropriate to put "People having miscarriage may feel sad" next to—it was like, "People having miscarriage may feel sad and have clots coming out of their vagina."*

While miscarriage and atrophic vaginitis are clearly different health issues, Eileen also spoke to how the same kind of resistance was evidenced when she was working on the article for *Cystocele*, a type of pelvic organ prolapse (POP):

> *And you know what? You know that there's a significant—there's a bunch of people who are sixty and older. I mean, a bunch of people. It's not ten percent. It's a lot. And even some of those folks have figured out how to press the "W" on their cell phone and try to find information on something. People are just going to keep getting better and better at that. And even if Grandma or Grandpa can't use their cell phone to find out things, their kids are going to. Their grandson or granddaughter. Grandma comes home from the doctor, and Grandma has a cystocele or rectocele or a fistula. Do you think people know what that is? But it's pretty significant to Grandma, and it really impacts her quality of life. Grandma may not be able to leave her house to do anything because she has these conditions. That information really needs to be there. Do you really think Grandma cares about the tissue that's been damaged or that the anterior vaginal wall needs to be connected to the tail bone? No, no. She cares about whether she can go back out at night.*

Like atrophic vaginitis, a cystocele is more likely to occur after childbirth and/or menopause. Like atrophic vaginitis, it is also poorly understood despite its prevalence and impact on quality of life.

"Silence equals death"

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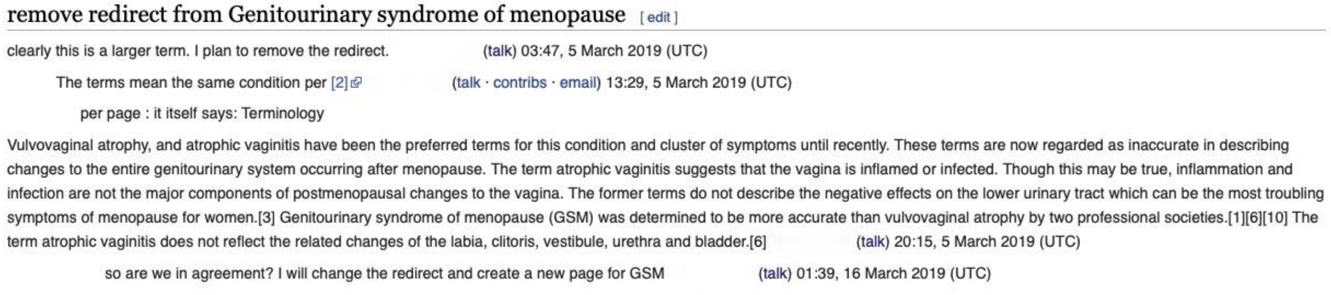
[55] There has also been a spike in "vagina shame" that is, perhaps, perpetuated by a fiscally-motivated push to fill the void created by a lack of knowledge about and attention to women's health care coupled with information communication technologies (ICTs) like social media platforms; see Moran & Lee, 2016 or the recent popular piece "How the internet gave me a vagina complex" by Thompson, 2019.

Carolyn began to edit the *Atrophic vaginitis* article in late 2007. When I asked her why she had edited the article initially, she said "nothing was there" when she started. She explained that she had wanted to draw from her lived experiences as a perimenopausal and menopausal woman to make health-related information more available to other women. She then told me a story about how the host of a dinner party—another woman—had asked her not to talk about menopause at the dinner table.[56] Carolyn was shocked. Carolyn said that, in her experience, women no longer learn about menopause from other women in their lives because "women don't share information across generations" and that, although menopause may not affect a third of women, "it impacts the other two-thirds to varying degrees—some very severe." She said she felt menopause was stigmatized in the United States to the point that it had become a taboo topic. After a pause, she added, "But if we don't talk about these things, silence equals death." Carolyn's feelings and perspective are not uncommon; researchers have noted these sentiments among other women (Nosek, Kennedy & Gudmundsdottir, 2010; Doubova et al., 2012) and have for a while (Posner, 1979).

Atrophic vaginitis or GSM?

As recently as March 2019, discussions on the talk page for *Atrophic vaginitis* reflect public misunderstandings and general confusion around the condition as it relates to genitourinary syndrome of menopause (GSM) (Nebel, 2016). See Figure 1.6.



remove redirect from Genitourinary syndrome of menopause [edit]

clearly this is a larger term. I plan to remove the redirect. (talk) 03:47, 5 March 2019 (UTC)

The terms mean the same condition per [2] (talk · contribs · email) 13:29, 5 March 2019 (UTC)

per page : it itself says: Terminology

Vulvovaginal atrophy, and atrophic vaginitis have been the preferred terms for this condition and cluster of symptoms until recently. These terms are now regarded as inaccurate in describing changes to the entire genitourinary system occurring after menopause. The term atrophic vaginitis suggests that the vagina is inflamed or infected. Though this may be true, inflammation and infection are not the major components of postmenopausal changes to the vagina. The former terms do not describe the negative effects on the lower urinary tract which can be the most troubling symptoms of menopause for women.[3] Genitourinary syndrome of menopause (GSM) was determined to be more accurate than vulvovaginal atrophy by two professional societies.[1][6][10] The term atrophic vaginitis does not reflect the related changes of the labia, clitoris, vestibule, urethra and bladder.[6] (talk) 20:15, 5 March 2019 (UTC)

so are we in agreement? I will change the redirect and create a new page for GSM (talk) 01:39, 16 March 2019 (UTC)

Figure 1.6 A screenshot of the March 2019 article talk page conversation about GSM and atrophic vaginitis with editors' user names removed. Note: The source referred to by the second commenter ([2]) and quoted on March 5 by the original poster is a 2017 article from the Mayo Clinic Proceedings entitled "Genitourinary Syndrome of Menopause: Management Strategies for the Clinician."

Atrophic vaginitis *is* sometimes GSM, but this conflation is misleading. Menopause is not the only cause of atrophic vaginitis (e.g., Palmer & Likis, 2003; Lester, Pahouja, Andersen, & Lustberg, 2015), and while GSM may include atrophic vaginitis, it also includes other conditions. During our interview, Sara said these kinds of conflations are often problematic on Wikipedia and that redirects are good examples:

> *I see things that are conflated that shouldn't be conflated. I don't think it's just women's health. I think women's health has it worse because there are so few of us writing in it, but it's just a general problem in medicine that people who don't know what they're doing are conflating things that shouldn't be conflated. People who don't know what they're doing are a large part of our problem […]*

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[56] As noted in Chapters 2 and 5, women can perpetuate sexism and, as in this case, the related shame and stigma associated with women's health.

However, as readers of Dan Savage's "Savage Love" column in Seattle's alternative newspaper *The Stranger* know, vaginal dryness and thinning of the vagina's lining can also be caused by chemotherapy, vaginal childbirth, and dips in estrogen during breastfeeding—causes that are also described on reputable health websites (e.g., MedlinePlus, MayoClinic.org)::

> I wanted to share some info following your "post-baby vaginal dryness" response. I have a 16-month-old son, and also experienced extreme discomfort that closely resembled shards of glass, and dryness during intercourse postpartum while breastfeeding. Something widely unknown, I learnt eight months into our nursing journey, was that breastfeeding hormones can cause pain during intercourse […]. A pelvic floor therapist cannot help with this and didn't help me. […] Breast feeding = low estrogen levels = vaginal dryness, inflammation of the vagina, thinned vaginal walls. […] Please spread the word! I tell every mom I know, this needs to be more widely known. The fact that birth has occurred for thousands of years and there are STILL unknown, not commonly shared symptoms/experiences/issues infuriates me. If men had babies I'm pretty sure every single possible detail would be on billboards.

As Savage's reader notes, "the fact that birth has occurred for thousands of years and there are still unknown[s]" is perplexing. However, some of these "unknowns" about childbirth (and menopause) may, in fact, be due to how knowledge production has been and continues to be gendered. For example, Savage's reader suggests that if men gave birth, "every single possible detail would be on billboards"; that is, she suggests patriarchal systems play a role in prioritizing certain kinds of information—information of interest and directly relevant to an idealized version of masculinity (i.e., one that is not interested in the embodied experiences of others)—and de-prioritizing other kinds of information (e.g., information about women's bodies and experiences).

Interestingly, some of the confusion about atrophic vaginitis and GSM results from a 2014 publication entitled "Genitourinary syndrome of menopause: New terminology for vulvovaginal atrophy from the International Society for the Study of Women's Sexual Health and The North American Menopause Society" in which the conference committee writes:

> The terms *vulvovaginal atrophy* (VVA) and *atrophic vaginitis* have been considered by many to be inadequate and inexact for describing the range of menopausal symptoms associated with physical changes of the vulva, vagina, and lower urinary tract associated with estrogen deficiency. […] Furthermore, the word *atrophy*, as used in both terms, has negative connotations for midlife women, and the word *vagina* is not a generally accepted term for public discourse or for the media. (p. 558)

In this excerpt we see the efforts of the committee to address the medical realities of the condition (GSM, specifically) as well as the negative connotations associated with the word *atrophy* (and, perhaps, with menopause more broadly) and perceived discomfort with the word *vagina*. Although the first two points are understandable, the latter is, on the surface, puzzling.[57]

Why is the word *vagina* stigmatized? And why are older (or *atrophic*) vaginas even *more* stigmatized? A comprehensive answer to the first question is beyond the scope of this chapter (and this dissertation work), but it is relevant to note that female genitalia have been stigmatized for centuries—often

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[57] When I selected *Atrophic vaginitis* as a possible candidate for object biography, I considered it to be *low* stigma because it is a condition that is not perceived as being preventable and/or controllable, and for which the patient is unlikely to be blamed. However, upon inspecting the history of the *Atrophic vaginitis* article and learning more about the condition, I realized female genitalia has *always* been stigmatized.

considered “dangerous” or “dirty.” For example, consider the history of chastity belts or the current practices of female genital mutilation (FGM) (see Whitehorn, Ayonrinde, & Maingay, 2002). Consider also *The Vagina Monologues* and the conversations, controversies, and criticisms it has sparked in the past twenty years (see Hall, 2005 for a thoughtful critique). Finally, consider Braun & Wilkinson’s (2001) study of seven dominant socio-cultural representations of the vagina including the vagina as inferior to the penis, as absence, and as disgusting. The authors argue these representations can greatly impact women’s sexual and reproductive health not only because they influence individual women but also because they influence medical practitioners; they conclude, “The health profession is in a position to challenge, or at least not reproduce, negative socio-cultural representations” (p. 27).[58] In short, the vagina and representations of it—including the word *vagina*—have been and are stigmatized largely because we live in patriarchal societies (see Chapter 2), and the results can have a significant impact on women’s health (e.g., Chrisler, 2011a; 2011b; 2013).

In response to the second question—and relevant to understanding *Atrophic vaginitis* as an object assembled, curated, used, and maintained within in a particular time and place—consider Bedor’s (2015) feminist critique of advertisements for Osphena, “an oral medication indicated for the treatment of dyspareunia—pain during sexual intercourse—encountered by some women […] who are post-menopausal,”[59] the continued medicalization of women’s bodies and related “faux-empowerment” (p. 51) “promotes pharmacological intervention into women’s natural aging processes *only when penetrative sex is jeopardized* [author’s emphasis]” (p. 51). Indeed, as of the writing of this chapter, the *Atrophic vaginitis* article includes an emphasis on penetrative sex in the following content (see bold text), which falls under “Treatment”:

> Symptoms of GSM will unlikely be resolved without treatment. Women may have many or a few symptoms so treatment is provided that best suits each woman. If other health problems are also present, these can be taken into account when determining the best course of treatment. **For those who have symptoms related to sexual activities, a lubricant may be sufficient.** If both urinary and genital symptoms exist, local, low-dose estrogen therapy can be effective. Those women who are survivors of hormone-sensitive cancer may need to be treated more cautiously. Some women can have symptoms that are widespread and may be at risk for osteoporosis. Estrogen and adjuvants may be best.
>
> [...]
>
> Some treatments have been developed more recently. These include selective estrogen receptor modulators, vaginal dehydroepiandrosterone, and laser therapy. **Other treatments are available without a prescription such as vaginal lubricants and moisturizers. Vaginal dilators may be helpful.** Since GSM may also cause urinary problems related to pelvic floor dysfunction, a woman may benefit from pelvic floor strengthening exercises. **Women and their partners have reported that estrogen therapy resulted in less painful sex, more satisfaction with sex, and an improvement in their sex life.**

As Bedor notes in her critique, framing menopause and resulting changes in hormones as a “deficiency” reinforces notions that aging bodies require certain kinds of medical interventions, particularly when “normal” (i.e., heteronormative and generally male-dominated; women should be “ready” for sex) sexual activities are considered markers for women remaining “healthy.”

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[58] Braun & Wilkinson (2001) do not explicitly state that they are focused on cisgender women’s sexual and reproductive health, but it is implied by their diction.

[59] See https://en.wikipedia.org/wiki/Ospemifene

Atrophic vaginitis, 2019

Since I began writing this object biography, however, *Atrophic vaginitis* has been re-categorized by WikiProject Women's Health as a C-class article of high-importance—a small step up from a start-class article.[60] After I conducted interviews, three participants worked on *Atrophic vaginitis*, improving the article's content and references and adding images, but their activity on the article has since stalled.

Carolyn has not edited *Atrophic vaginitis* since we spoke in 2017. She has, however, been actively editing other articles unrelated to women's health. Interestingly, when I asked Carolyn about contributing to Wikipedia and being a part of the community, she talked about attending meet-ups where she lives. She said they were often "very testosterone rich environments" with a lot of men "butting heads like rams." She said she had noticed that women's health content on Wikipedia had begun to improve "about five years ago" (2012), but that it had also become increasingly medicalized. She concluded that writing women's health content was not for her because it was "difficult to argue with expertise." (She is an expert in a different field of study.) And, yet, despite perceived said expertise on Wikipedia, activity on *Atrophic vaginitis* has languished.

In summary, considering the life-history of the *Atrophic vaginitis* article on the English language Wikipedia tells us how it has been neglected, especially during the first decade of its life when Wikipedia experienced a surge in editing (Halfaker et al., 2013). But it also tells us something about the condition itself and how it has been and continues to be stigmatized despite its prevalence and impact. Finally, it tells us about how the editor community may reinforce dominant patriarchal, heteronormative, and medicalized conceptions of women's bodies even as they age.

Vaginal cancer

Today (July 2019), if a woman uses a popular search engine to look for information about vaginal cancer, she may wonder why Wikipedia does not appear in the first page of results. She may see links to Cancer.gov, American Cancer Society, or Medical News Today, but Wikipedia is conspicuously absent. If she uses Google Scholar to search for publications about vaginal cancer, she will find more than 650,000 results (excluding citations and patents) in less than a half a second (or, in my case, in less than 0.05 seconds). Many of these results will link to open source publications made available from the Wiley Online Library or the National Institutes of Health (NIH). If Wikipedia is the world's largest online encyclopedia, the English language Wikipedia is one of the top ten websites in the world, and peer-reviewed research about vaginal cancer is freely available, why does Wikipedia have so little to say about it?

In the following section, I examine the history of the *Vaginal cancer* article to tell its life-history and to understand how stigma (e.g., health-related stigma) and participatory gaps—particularly race and age-related gaps—interact with women's health content on Wikipedia. I begin with a brief overview of the epidemiology of the disease and then present a series of vignettes in which I discuss the life of the article in relation to men's health articles, stigma, and potential racial bias on Wikipedia.

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[60] The article remains categorized by WikiProject Medicine as a start-class article of mid-importance.

The natural history and epidemiology of vaginal cancer

Vaginal cancer is considered a rare disease. According to the American Cancer Society, approximately 5,350 new cases of vaginal cancer will be diagnosed and approximately 1,430 women will die from the disease in the United States in 2019. In contrast, an estimated 268,600 new cases of breast cancer and 41,760 related deaths are expected in women in 2019 in the U.S.[61]

There are two kinds of vaginal cancer: (1) squamous cell carcinoma (SCC), which is the most common type, and (2) adenocarcinoma, which is more likely to appear in postmenopausal women or women who were exposed *in utero* to diethylstilbestrol, a synthetic estrogen prescribed from the late 1930s until the early 1970s to prevent miscarriage (e.g., Hatch et al., 1998; Newbold, 2004). Althhough vaginal cancer is rare, access to healthcare and early screening is key to prevention and early diagnosis. Survival rates are dependent upon a range of factors, some of which are considered "modifiable" (e.g., smoking, excessive body weight):

> We observed that incidence rates of invasive vaginal SCC varied by race and ethnicity. The variation may reflect racial and ethnic differences in oncogenic HPV infection and in other risk factors. [...] Other factors that have been associated with the risk of vaginal cancer include low socioeconomic status, multiple sex partners, a family history of anogenital cancer, marital status, and cigarette smoking. [...] Our study also revealed that, within the same stage of vaginal SCC, 5-year relative survival rates were lower among black women than among white women, and they were lower among older women than among younger women. (Wu et al., 2008, p. 2878)

As Wu and colleagues note, vaginal cancer impacts women differently, usually along racial and ethnic lines. Similarly, Shah and colleagues (2009) found incidence rates "increase sharply with age and also vary considerably by race/ethnicity." Because many women with vaginal cancer are asymptomatic and the most common clinical presentation is vaginal bleeding (which a woman may assume is related to menstruation, menopause, atrophic vaginitis, or GSM), the disease may go undiagnosed. Finally, as the medical resource UpToDate notes, there are no randomized trials outlining treatment for vaginal cancer.[62] However, there are several primary research articles and narrative reviews describing vaginal cancer in the biomedical literature (e.g., Shrivastava et al., 2015; Rajaram, Maheshwari & Srivastava, 2015; Shetty & Menias, 2017).

The birth of an article

In 2007, six years after its start, the English language Wikipedia consisted of more than 1.5 million articles; the number of active English language Wikipedia editors peaked at more than 50,000 and has been in decline since (e.g., Suh et al., 2009). *Vaginal cancer* came into existence at the height of editing. On February 21, 2007, a user (hereafter referred to as Editor Y) from the Netherlands who had been editing with a registered account for a little more than two years created the *Vaginal cancer* article. The first version of the article consisted of four sentences and one reference. Editor Y categorized the article as belonging to both "Disease stubs" and "Gynaecology." Additionally, they included an Infobox (Infobox_Disease), listing classifications and references with associated hyperlinks: Speciality

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[61] See https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2019/cancer-facts-and-figures-2019.pdf

[62] See https://www.uptodate.com/contents/vaginal-cancer. UpToDate attributes the lack of randomized trials to the rarity of the disease, which is an assumption I return to later.

(oncology); DiseaseDB (13693); MedlinePlus (001510); and eMedicine (med/3330). Editor Y also created wikilinks (hyperlinked words that redirect to other Wikipedia articles) for six words in the article: *cancer*, *vagina*, *cervix*, *uterus*, *squamous cell carcinoma*, and *adenocarcinoma*. Within two minutes of creating the article, Editor Y made one final edit, changing “Gynaecology” to “Gynecology.” Aside from reverting another editor’s edits in 2010, Editor Y never edited *Vaginal cancer* again; however, they have remained in the community—primarily editing medical and health content.

Vaginal cancer vs. Bart Simpson

In contrast to *Vaginal cancer*, the article for Bart Simpson, a fictional cartoon character, was created six years prior in May 2001. By February 21, 2007, Bart Simpson’s article contained an Infobox and several sections, including sections devoted to “Personality” and “Cultural influence.” Consider also that by February 21, 2007, the article for Linux, a collection of free and open source software systems, contained an Infobox, images, and multiple sections, including “History,” “The Linux name,” “Philosophy” and “Distribution.” Today, *Bart Simpson* is a Featured Article (~0.1% of all articles) with semi-protected status (unregistered IP addresses and user accounts that are not autoconfirmed cannot edit the article), and the *Linux* article is under pending changes protection (all edits by unregistered IP addresses and new users are held for approval by an editor with reviewer rights).

And while comparing the birth of *Vaginal cancer* to *Bart Simpson* and *Linux* may be comparing proverbial apples to oranges, consider that the *Testicular cancer* article was created in August 2003 and by February 25, 2007, contained an Infobox and multiple sections, including “Symptoms and early detection,” “Famous survivors,” and “Famous victims” (the latter two sections were removed in 2009). Relatedly, the article *Penile cancer* was created in September 2003 and contained multiple sections by February 2007. (See Table 3.6.) Like vaginal cancer, both testicular and penile cancer are considered rare (e.g., Manecksha & Fitzpatrick, 2009; Douglawi & Masterson, 2017). However, unlike vaginal cancer, researchers have conducted extensive randomized trials for both testicular and penile cancer (e.g., Fossa et al., 1999; Jones et al., 2005; Albers et al., 2008; Lander et al., 1997; Pagliaro et al., 2010).

The first decade of life

During the 12 years of its life, *Vaginal cancer* has been edited 243 times with 44 edits by anonymous users (unregistered IP addresses) and 24 edits by bots. Roughly 105 editors have touched the article (adding content, templates, images, or references and/or reverting other editors’ contributions) with the most activity on the article taking place in 2017 after I conducted interviews.

Like *Atrophic vaginitis*, the *Vaginal cancer* article has been repeatedly vandalized with edits like “Hilary Knop likes to lick vaginal cancer” and “RYAN KAGEYAMA ENJOYS VAGINAL CANCER!” One unregistered IP address changed every instance of “vagina” to “cunt,” another tried to embed a YouTube video into the article, and an account that repeatedly added “tim burton is a flaming man lover” to the *Tim Burton* and *Lithosphere* articles also edited *Vaginal cancer* to include the statement “i like vaginal cancer” repeated hundreds of times. All of these edits were reverted by registered users or bots within seconds.

Although many instances of vandalism on this article involve what can best be described as “revenge edits” in which unregistered IP addresses insult people using their first and last names, a few instances of vandalism are what Shanna, who has been editing Wikipedia for more than a decade, would describe as instructive:

> *I did value having articles being able to be edited anonymously by IPs or by non-logged in users because they would tend to—you know, if somebody comes to an article, and they're confused by something, they might try to edit it, and even if their edit wasn't helpful, sometimes you could parse out, "Oh, this part of the article is confusing people." And, on some of the more popular articles, there were so many malicious edits that get locked out, and then we lost the average user giving feedback on it, which I guess is a struggle as it grew—as Wikipedia as a whole grew.*

For example, one account added the following text to the lead paragraph:

> It happens due to unsafe sex. Many-many times of insertion of penis also creates cancer in vagina. OK!!!. So don't do it […] It also happens due to seeing of porn videos or films.

If we take Shanna's approach, we might view this act of vandalism as an expression of confusion about the causes of vaginal cancer (HPV can be spread without penetration and, while safe sex reduces risk, HPV can still be spread even when condoms are used) as well as confusion about human sexuality in general (vaginal cancer "also happens due to seeing of porn") and, thus, a catalyst for accurate, accessible information on Wikipedia.

Crickets

As of the writing of this chapter, the talk page for the *Vaginal cancer* article has only two posts. The first post was added by a user (hereafter referred to as Editor Z) in February 2017—a decade after the article was created—and reads:

> Hello, I am a student from Rice University interested in writing a page on women's cancer disparities in the U.S. and I hope to elaborate more on vaginal cancer disparities based on socioeconomic status, race, sexual orientation, geographical factors, and more. Please feel free to check out my talk page for my page proposal or to provide me any feedback or suggestions. Thank you!

Though Editor Z did not receive any responses to her post and never edited *Vaginal cancer*, she created an article about gynecologic cancer disparities in the United States as a part of her coursework for Human Development in Global and Local Communities at Rice University.[63]

The second post to the article talk page was added by another user (hereafter referred to as Editor W) who, to date, is responsible for the most edits and the greatest content contribution (measured in bytes) to the *Vaginal cancer* article. Editor W posted the following in December 2017:

> Relevant sources:
>
> http://www.sciencedirect.com/science/article/pii/S2352578916300479

She then added a second link to another source in March 2018. Her post did not receive any comments. Consider that the talk page for *Testicular cancer* has 21 unique posts, many with responses, and that the

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[63] During the writing of this chapter, I added the template for WikiProject Women's Health to the talk page for the *Gynecologic cancer disparities in the United States* article as it had not been categorized or assessed by the project.

talk page for *Penile cancer* has 13 unique posts, several with responses. As noted in Chapter 3, a Wikipedia article talk page is the place where editors discuss the article, so it is telling that the talk page for *Vaginal cancer* is so quiet.[64]

Stigma

Drawing on Goffman's seminal work (1963), we can operationalize *stigma* as he did: "the situation of the individual who is disqualified from full social acceptance" (p. 9). Goffman goes on to identify three types of stigma: physical deformities, individual deviancies, and tribal identities—or stigmatized conditions related to race, ethnic origin, religion, sex, etc. However, as Weiss, Ramakrishna & Somma (2007) note, though highly influential, the language used in Goffman's typology is outdated, his focus is broad and not directly related to health, and his framework—centered on social interactions rather than social structures—is not particularly useful for understanding stigma in cross-cultural contexts or for understanding how social structures (such as a patriarchal state) shape social interactions. Extending Goffman's work, they suggest the following conceptualization of *health-related stigma*:

> Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g., race, ethnicity, sexual preferences), may also affect health […].[65]

As noted above, HPV—a sexually transmitted infection (STI)—is a risk factor with a strong relationship to vaginal cancer (Daling et al., 2002); consequently, the disease is frequently stigmatized due to historical (and persistent) double standards about women's sexuality (e.g., Crawford & Popp, 2003; Bay-Cheng, 2015; Farvid, Braun, & Rowney, 2017; Espin, 2018) and the resulting *gendered* stigma associated with sexually transmitted diseases (STDs) and STIs in general (e.g., Nack, 2000; Nack, 2002; Lichtenstein, 2003; Loutfy et al., 2012), and particularly with HPV (e.g., Shepherd & Gerend, 2014; Daley et al., 2016).[66] Despite HPV being highly prevalent—it is the most common STI in the United States; roughly half of American adults have been or will be infected—men with HPV are unlikely to know they have the STI as there is currently no recommended or FDA approved test for men (with the exception of cytological anal testing for men who have sex with other men), particularly for high-risk subtypes that do not present symptoms (i.e., warts or lesions). In contrast, in the United States women ages 21-65 are encouraged to have the Papanicolaou test (more commonly known as a Pap smear) every three to five years, and a test for HPV is routinely included when a Pap smear is conducted on a patient over 30 years of age.[67] This discrepancy in protocols and measurements places the burden of knowledge

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[64] I have used gender specific pronouns for both Editors Z and W because they specific their genders on their user pages.

[65] See Chapter 4 for more information about how I operationalized stigma for the purpose of sampling articles for potential object biographies.

[66] As a woman who dated while HPV positive, I can attest that disclosing HPV positive status to men—men who, given prevalence, are likely to have HPV—can result in negative responses.

[67] See https://www.cdc.gov/cancer/cervical/pdf/guidelines.pdf

and potential action (e.g., informing potential partners of HPV status, using a female condom—which is more effective in preventing the spread of HPV—rather than a male condom, scheduling and undergoing a colposcopy) on women. In fact, researchers suggest that HPV has been consistently framed as a "women's disease […] leading to the feminization of HPV" (Daley et al., 2016) despite its prevalence among and potential impact on men.

Furthermore, as noted by researchers (Lebel & Devins, 2008), people with cancer who perceive themselves as somehow responsible—as engaging in behaviors that are perceived to have contributed to the disease—often experience both enacted and felt stigma. That is, they may be stigmatized by others (e.g., family members, friends, healthcare providers) as well as experience feelings of shame and guilt; the latter often leads to a reluctance to seek help and receive treatment. Although stigma associated with vaginal cancer has been understudied, the stigma associated with cervical cancer has received a fair amount of scholarly attention in the last several years; given the role of HPV in both cervical and vaginal cancer, we can draw on this body of work to understand the ways in which people may perceive women with vaginal cancer. For example, one study found that when participants knew about the link between HPV and cervical cancer, they reacted more negatively to women with cervical cancer, registering "a stronger disgust response" (Shepherd & Gerend, 2014, p. 107). In addition to the stigmatization of women's sexuality and STIs like HPV, "modifiable" factors (e.g., smoking, obesity) associated with vaginal cancer may also be stigmatized. In fact, obese women are less likely to seek gynecological cancer screening in general due to poor treatment, embarrassment, unsolicited advice, and/or the size of medical equipment (Amy, Aalborg & Keranen, 2004).

When Sara and I talked about trans and women's health information on Wikipedia, and I asked her why she thought certain kinds of information were missing, she replied:

> *First of all, I think it's stigma. It's stigmatized information. It's—there's just not a lot of people with the expertise to write about it, and people don't want to fight.*

Sara's comment sheds light on Carolyn's observation that she no longer writes women's health content because it is "difficult to argue with expertise." Although Sara and Carolyn both use the word *expertise*, Carolyn referred specifically to medical doctors, whereas Sara referred to people who are experts in *women's health* and *trans health*. Sara went on to say that trans health content on Wikipedia was "hot garbage" and that women's reproductive and sexual health information was more likely to be subject to gatekeeping in addition to being stigmatized: "Gynecology in general is a very—just a field that is very aggressive in a lot of ways and very inaccessible to outsiders." Could it be that these many layers of stigma have contributed to the neglect of *Vaginal cancer* on Wikipedia? Or could it be that gatekeeping by different kinds of experts (e.g., medical professionals, expert editors) is the issue? I return to these questions in the Discussion section below.

The role of race

Health-related stigma and, consequently, detection and treatment can be exacerbated by a range of factors, including race. In the case of vaginal cancer, researchers have found that "African Americans with invasive vaginal cancer have poorer survival compared with Whites even after adjusting for age, histology, stage, grade, lymph node metastasis, lymphadenectomy and treatment modality" (Mahdi et al., 2011). In general, women of color who have cancer experience differences in treatment (e.g., Glanz et al., 2003; Ashing-Giwa et al., 2004), and multiple barriers to preventative care, including cultural and personal barriers (e.g., language, religion, concepts of modesty, shame), socioeconomic barriers, and institutional barriers, including a lack of physician recommendations for screenings (e.g., Glanz et al., 2003; Siegel et al., 2011).

According to the *Racial bias on Wikipedia* article[68], the participatory racial gap coupled with the historical bias of secondary sources are to blame for the underrepresentation of people of color on Wikipedia. The article talk page includes the following exchange between a registered IP address and an editor (User 1 and User 2), which points to participatory gaps, secondary sources (referred to as *R.S.,* or reliable sources), and Wikipedia's policies:

> It is hard to add any content to expand this article because there is a loop. Wikipedia is White dominant, African editors are pushed out. When they add ref reflecting either evidence of racism on wikipedia it is not a R.S. So we have a loop going. How do you write an article on Wikipedia about a problem with Wikipedia which is being accused of Racism? It creates a paradox. Esp when WIki policy on so-called RS marginalizes non-White publications, and content from independent sources. And all of this is moderated by the very people being accused of racism.—[User 1] 08:16, 24 September 2018 (UTC)
>
>> Here is a proper source, but guess what it fails Wiki Whites criteria. So all of this African opinions are marginalized as the opinions of crazy disgruntled editors . Keep it up. [Wiki is Racist in Full color https://medium.com/@kamy1/racist-wikipedia-da005c564d13] — Preceding unsigned comment added by [User 1] 12:42, 24 September 2018 (UTC)
>>
>>> Not at all sure how people can be certain about racism claims since most editors are anonymous. If some editors are truly being hostile, report them. We want Wikipedia to be open and welcoming. That is our aspiration, at least. [User 2] 19:14, 12 February 2019 (UTC)

As noted in Chapter 3, although there have been several community-based initiatives designed to increase the representation of people of color on Wikipedia (e.g., AfroCrowd, Black Lunch Table), there has been little to no research about the English language Wikipedia's participatory racial gaps. One exception is Shaw & Hargittai's 2018 paper about the participation pipeline. Though not limited to a study of race, the authors consider "several racial/ethnic identity categories (Black, Hispanic, Other)" (p. 155) as salient factors in the "intermediate stages" of the pipeline: "visiting Wikipedia and/or knowing Wikipedia can be edited" (p. 161). Given what we know about the epidemiology of the disease, could race play a role in the neglect of the *Vaginal cancer* article? If so, is it as simple as "Black, Hispanic, Other" not "knowing Wikipedia can be edited"? User 1's posts above tell a different story.

Vaginal cancer, 2019

After I conducted interviews, two participants worked on the *Vaginal cancer* article. However, since its birth in 2007, the article has remained a "low" quality article, moving from stub to start-class over 12 years. Today, the *Vaginal cancer* article consists of 14,192 bytes, *Penile cancer* consists of 19,090 bytes, and *Testicular cancer* consists of 45,089 bytes. Is there really so little to say about vaginal cancer in comparison to similar rare cancers that directly impact male genitalia? Based on the amount of publicly available peer-reviewed literature about the disease, the lack of engagement with the article over the last 12 years, and the role of stigma and race in the epidemiology of vaginal cancer, I would argue it is much more complicated than that. In summary, considering the life-history of the *Vaginal cancer* article enables us to think about how existing biases interact with the design (broadly speaking)

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[68] See https://en.wikipedia.org/wiki/Racial_bias_on_Wikipedia

of a sociotechnical system like Wikipedia to reproduce and reify health disparities. This is a topic I take up in the Discussion section below.

Women's health

While it may seem strange to include *Women's health* as an object biography here given that the article as it stands today is so broad in its coverage, when we examine the first 12 years of the *Women's health* article's life, we learn several things about its life-history. First, we learn the article was created in a way that framed women's health as "specific to human female anatomy." Second, we learn that, though the article was maintained at a superficial level, its content was largely neglected for many years with content changes made only in relation to other articles. Third, we learn WikiProject Medicine considered the article (and, thus, the topic) to be "low priority" as recently as 2008. Finally, by examining the last few years of the life of the *Women's health* article, we learn the time, attention, and care of a few dedicated editors can make a difference.

In the following section, I examine the history of the *Women's health* article to tell its life-history and to understand how production and neglect impact women's health content on Wikipedia more broadly. I begin with a description of its birth in 2004. I then focus on the first twelve years of its life—before it became a Good article.

An abysmal article is born

When I began researching women's health information on Wikipedia, I reached out to members of WikiProject Women's Health to ask if they would be willing to talk to me. William and I exchanged several emails before we agreed on a date and time to talk. In one of his earliest emails (July 2016), William wrote:

> The actual article—*Women's health*—is abysmal, and a comment on the talk page says it all, suggesting it be just called Gynecology. This is the wombs on legs myth that has had such a detrimental effect on women's health and which I have campaigned against all my life.

The article *Women's health* was created in 2004 by an editor (hereafter referred to as Editor A) who, according to their user page, is now a postgraduate student in neuroscience and who, according to their user contributions, was extremely active in 2004 with more than 9,000 edits that year. In its first incarnation, the article read:

> Women's health generally refers to health issues and matters specific to human female anatomy. Such issues often relate to the female genitalia, breasts and other physiological structures not found in the human male.
>
> It can also be relevent [*sic*] by conditions relating to hormones and other chemicals specific to, or notable in, the female.
>
> The most notable female health matters include menstruation, child birth, menopause, breast cancer, and so forth.

For approximately three years (May 2004 to April 2007), the article remained in this state, perpetuating what William described as the "wombs on legs myth" and normalizing a conception of women's health limited to the care, management, and control of female reproductive organs: as William later said in an interview, "boobs and tubes." While the article was maintained, it was not improved—despite the fact, as noted in the object biographies above, that the number of people editing Wikipedia peaked in 2007 (Halfaker et al., 2013).

Occasionally the article would be vandalized ("your mom likes to eat children") or the target of promotional edits ("Online since 1996 http://www.obgyn.net OBGYN.net is the largest global website […]"), but editors and bots quickly reverted these changes. As one editor (hereafter referred to as Editor X) who corrected these kind of edits notes on their user page, "My original plan was to contribute articles, but I got distracted by the instant gratification of RC patrol." (Here, "RC patrol" refers to Recent Changes patrol: a Wikipedia community portal that allows users to monitor recent changes across the encyclopedia.) Indeed, fighting vandals (people who deliberately intend to disrupt Wikipedia's processes or undermine the goals of the project) takes a significant amount of time and attention, and some Wikipedia editors devote themselves to the task (Welser et al., 2011). Additionally, as Editor X admits, fighting vandals provides a kind of "instant gratification" that creating content adhering to Wikipedia's numerous policies (e.g., Neutral Point of View, No original research, Verifiability) does not. Of the 60 edits in the first three years of the article's life, 22 were acts of vandalism or promotion and 14 were edits to correct these acts, which means 60% of all edits in the first three years were either disruptions or repairs. Why were editors maintaining but not improving *Women's health*? What were they working on instead?

During our interview, Navi offered the following hypothesis:

> *It could be because not many people are interested to read about women's health that not many Wikimedians are working on women's health. Many people are, like, writing controversial things over there. So, when you write something controversial, you attract a lot of people. When you write—when you are writing science, you are just writing the facts, and you do not have any opinions to push there, so articles related to science in general create less of a fuss and less talk page discussion than articles related to personalities and people.*

Navi's hypothesis resonates with research. For example, Spoerri (2007) found that the most popular pages on Wikipedia in 2007 fell into categories like Entertainment (43%), Politics and History (15%), Geography (12%), and Sexuality (10%), a category which included pages about sexual anatomy, sexual practices, and porn stars (Spoerri, 2007). Similarly, Kittur, Chi & Suh (2009) found that articles related to "Culture and the arts" dominated Wikipedia (30%) in 2008, followed by articles related to "People and self" (15%), and "Geography and places" (14%). Articles related to "Health and fitness" comprised only 2% of all Wikipedia articles in 2008 (Kittur, Chi & Suh, 2009). Perhaps, then, it is not surprising that so few people were working on *Women's health*; their attention was elsewhere.

Opportunistic edits

Three years after the article's creation in April 2007 an editor (hereafter referred to as Editor B) added the following text:

> They [women's health issues] can also include medical situations in which women face problems not directly related to their biology, for example geneder-differentiated [*sic*] access to medical treatment.
>
> Women's health is an issue which has been taken up by many feminists, especially where reproductive health is concerned. One example of this is the Cartwright Inquiry in New Zealand, in which research by two feminist journalists revealed that women with cervical abnormalities were not receiving treatment, as part of an experiment.

> The women were not told of the abnormalities and several later died. In many countries feminists have campaigned for the right to legal and safe abortion, arguing that it is a health rather than a moral issue. In countries where contraception is difficult to access, campaigns for readily available contraception are conducted on the same lines. Conversely, there have also been campaigns against potentially dangerous forms of contraception such as the IUD.

According to their user page, this editor lives in New Zealand and has a Ph.D. in history from the University of Auckland. In April 2007, less than an hour before expanding *Women's health*, this editor was working on *List of feminists*. Shortly after expanding *Women's health*, this editor then created an article for Sandra Coney, a journalist involved in the Cartwright Inquiry:

> […] a New Zealand feminist and women's health campaigner. She is best known for her co-authorship (with Phillida Bunkle) of a Metro magazine article which alleged that women had been experimented on, without their consent, at National Women's Hospital in Auckland.

One year later, another editor (hereafter referred to as Editor C) without a user page added the following text:

> Some health and medical research advocates, particularly the Society for Women's Health Research in the United States, define women's health more broadly than issues specific to human female anatomy to include areas where biological sex differences between women and men exist. Research has demonstrated significant biological differences between the sexes in rates of susceptibility, symptoms and responsiveness to treatment in many major areas of health, including heart disease and some cancers.

This editor was active for three years (2007-2010) and, apart from two edits to *Women's health*, worked solely on the article for *Society for Women's Health Research*, "a national nonprofit dedicated to promoting research on biological differences in disease and improving women's health through science, policy, and education."[69] Given the editor's user name, which is an abbreviation for the Society for Women's Health Research, and their edit history, we might assume they were employed by or had some affiliation with the Society for Women's Health Research.

These two significant content changes in 2007 and 2008 indicate the editors (Editor B and Editor C) may have used *Women's health* in opportunistic ways. While Editor B has more than 5,900 live edits (edits that have not been reverted) and was editing as recently as 2018, Editor C has only 34 live edits and has not edited since 2010. Editor B, despite their continued work on Wikipedia, contributed to *Women's health* only once and only in relation to *List of feminists* and *Sandra Coney*. It may be that both editors recognized the value of connecting newly created content about the Society for Women's Health Research or Sandra Coney and the Cartwright Inquiry to existing articles and lists and this—rather than improving *Women's health*—was their motivation. Or it may be that Editor B took an *eventualist* perspective, which was common among early Wikipedia editors: "Eventualism is a tendency amongst Wikipedians focusing on the eventual value of Wikipedia in the long-term rather than the immediate value."[70] This explanation would explain why Editor B added a broader definition of women's health to the article but did not edit the article as a whole. Although it is impossible to know Editor B and C's intentions, we can ask questions based on their edits: What did they want *Women's health* to be? Why did they choose not to edit the first few sentences, potentially shifting the tone of the entire article? Were they editing *Women's health* with care?

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[69] See https://swhr.org

[70] See https://meta.wikimedia.org/wiki/Eventualism

Seven years of stagnation

Between 2008 and 2015, the article changed very little content-wise and, on the surface, it seemed to languish. There were 126 edits in seven years (approximately 15-16 edits per year); 20 edits were reversions of prior edits (e.g., acts of vandalism or promotion) and seven were edits by bots (one reversion; the other six instances of routine maintenance). Of the remaining 99 edits, less than a third were content-related (*vs*. tweaks to categories or links), and the majority of these edits were either trivial (less than 100 bytes) or puzzling one-offs. For example, in 2010, an editor (hereafter referred to as Editor M) added a photograph he had taken of the Women's Health Protective Association monument in Riverside Park in Manhattan, New York City to the article. This was the article's first image and the only contribution Editor M ever made to *Women's health*; however, in his edit summary, he failed to explain his rationale for adding the image to the article. In fact, he wrote nothing at all. (This image would be removed six years later in 2016 when another editor noted it was "unrelated to the text.")

However, when we look more closely at the revision history for *Women's health*, we see that a few editors—using unregistered IP addresses or new accounts—were trying to shift the framing of topic. For example, one editor (hereafter referred to as Editor N) who created a registered account but did not create a user page, contributed the following text:

> In 1973, the Supreme Court decriminalized abortion through the landmark case Roe v. Wade. This opened the door to women's health activists within the Women's Liberation Movement to organize and open feminist abortion clinics. These clinics opened in cities and towns around the country. In addition, these women explored activism in other areas of women's health: sterilization abuse, lesbian health care, feminist psychotherapy, birthing practices and midwifery, workplace health issues and access to new or alternative methods of contraception, to name a few. As a result, a number of regional and national grassroots organizations were established to work on identifying and changing abuses and inequities in health care delivery.
>
> At the same time, woman-centered health centers focused on providing alternatives to the existing patriarchal model of gynecological care and offered access to care for underserved populations. Through education and teaching breast and cervical self-exam techniques (self-help), they encouraged women to become participants in and more demanding consumers of health care. CWHC was one of the first of these clinics and has continued to offer this model of care for over 30 years.

However, in adding this text, Editor N, perhaps unknowingly, committed a copyright violation when they copied and pasted a passage from the Women's Health Movement page on the Chicago Women's Health Center's (CWHC) website.[71] Editor N's contribution was reverted eight hours later.

In June 2015, several edits by unregistered IP addresses began to shape the lead paragraph of the article, reframing women's health to extend beyond "health issues and matters specific to human female anatomy" and evidencing familiarity with Wikipedia's policies. Unlike Editor N, these editors included descriptive edit summaries like "revise challenged definition and expand a bit, per multiple MEDRS"[72] and reinstated and tweaked prior edits that had been reverted.

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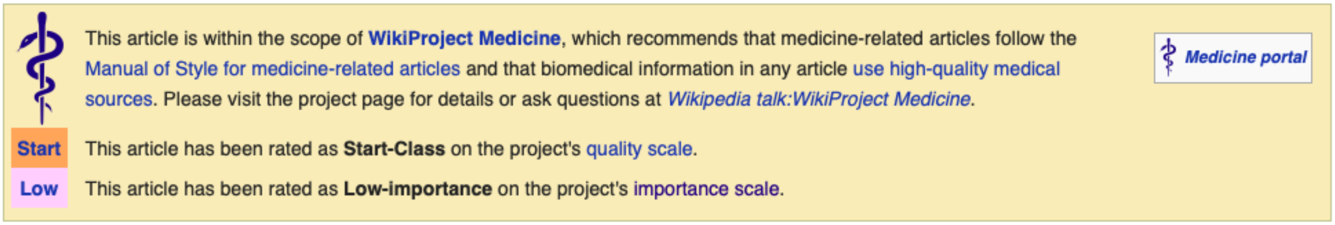
[71] See http://www.chicagowomenshealthcenter.org/about/womens-health-movement

[72] Here, MEDRS refers to the content guideline "Identifying reliable sources (medicine)." See https://en.wikipedia.org/wiki/Wikipedia:Identifying_reliable_sources_(medicine)

What is women’s health, anyway?

Carefully examining the *Women’s health* article and its associated talk page returns us to the question of how women’s health is defined and prioritized. For example, in 2007, an editor applied a template that read: “This human reproduction article is a stub.” Yet, between 2004 and 2006, the only talk page comment about *Women’s health* was: “yo yo yo. Whats [*sic*] up, I hate womes [*sic*] health.” This comment, the only edit by an unregistered IP address, was not removed until 2008 by an editor (hereafter referred to as Editor D) who, at the same time, also added the WikiProject Medicine template, indicating the article was both Start class and low priority (see Figure 1.6).



This article is within the scope of **WikiProject Medicine**, which recommends that medicine-related articles follow the Manual of Style for medicine-related articles and that biomedical information in any article use high-quality medical sources. Please visit the project page for details or ask questions at *Wikipedia talk:WikiProject Medicine*.

Start This article has been rated as **Start-Class** on the project's quality scale.

Low This article has been rated as **Low-importance** on the project's importance scale.

Figure 2.6. The WikiProject Medicine template applied to the Women’s health article in 2008. A template like this indicates a WikiProject’s interest in a particular article as well as how the project rates the importance of the article.

According to WikiProject Medicine, *Start-Class* means, “an article that is developing, but which is quite incomplete. It might or might not cite adequate reliable sources.” *Low-importance* means:

> Article may only be included to cover a specific part of a more important article, or may be only loosely connected to medicine. Subject may be specific to one country or part of one country, such as licensing requirements or organizations. This category includes most of the following: very rare diseases, lesser-known medical signs, equipment, hospitals, individuals, historical information, publications, laws, investigational drugs, detailed genetic and physiological information, and obscure anatomical features.

Given the broader history of women’s health (see Chapter 2) and the history of WikiProject Women’s Health (see Chapter 5) it is, perhaps, not surprising that the *Women’s health* languished for more than a decade and that, as recently as 2008, the article was rated as “Low-importance.” However, by WikiProject Medicine’s own metrics, *Women’s health* does not meet requirements for “Low-importance.” Arguably it is more than “loosely connected to medicine” and is not “specific to one country or part of one country.” Why, then, did WikiProject Medicine consider *Women’s health* to be low priority?

In 2012, Editor D commented:

> A recent edit moved this article to Women’s health issues. I reverted it because women’s health is a common term used to refer to this area. It is also more general than Women’s health issues (health can refer to the general state of health/wellness, rather than to specific issues or problems). Should delay splitting into subareas of women’s health (health in general, issues, whatever), until the article is sufficiently large to warrant division.

Editor D’s comment was in response to another editor’s attempt to change the title of the article to *Women’s health issues*. In the latter’s edit summary, he[73] wrote, “refers to health ISSUES specific to

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[73] I have used a gender specific pronoun here because this editor indicates his gender on his user page.

human female anatomy," indicating that—even eight years after the article's creation—some editors were still convinced that women's health was limited to "boobs and tubes." In fact, two years later in 2014, an editor who, according to their user page prefers to edit under an unregistered IP address, added the following comment to the article talk page:

> Imo, the scope of this page requires a careful rethink (per WP:SCOPE) as a first step to improvement. At the time of writing, the main definition of "Women's health" (ie [*sic*], literally, the health *of women*, per [1]) seems to fit "Gynecology" (per [2]).

In this comment, WP:SCOPE links to an essay describing how editors should determine the scope of an article. The first in text citation ([1]) links to the MeSH ID for Women's Health introduced in 1991 ("The concept covering the physical and mental conditions of women") while "Gynecology" links to the Wikipedia article by the same name, and the second in text citation ([2]) links to the MeSH ID for Gynecology ("A medical-surgical specialty concerned with the physiology and disorders primarily of the female genital tract, as well as female endocrinology and reproductive physiology"). This was the first dissenting voice on the article talk explicitly challenging the definition of women's health as "specific to human female anatomy."

Two years later, another editor replied:

> The worst possible thing that happened to Women's health was to reduce it to gynaecology [*sic*], leaving women very badly served in all other areas of health. You are correct that a more holistic approach is "Health of Women", but the title serves its purpose.

Within months of this last comment, *Women's health* would change radically in its scope and be awarded the Good article icon on November 10, 2016.[74]

They're not all good articles

Good articles on the English language Wikipedia account for only 1 in every 199 articles. To become a Good article, an article must be "well-written, verifiable with no original research, broad in its coverage, neutral, stable (no edit warring or content disputes), and illustrated."[75] Additionally, it must go through a review process, which involves nomination by one editor and review by another editor who has not made significant contributions to the nominated article. This process is similar to an academic peer review with the exception that only one reviewer is required. For a Wikipedia article, the only thing better than becoming a Good article is to become a Featured article (FA). As of the writing of this chapter, there are only 5,567 Featured articles on the English language Wikipedia: approximately 0.1%.

Women's health, 2019

Today, *Women's health* is a Good article. This is thanks to William. Although William first edited *Women's health* in 2008, he did not edit the article again until 2016 after I contacted him via email. Over

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[74] In contrast to Women's health the Men's health article was created two years later in April 2006, and today, Men's health is still a Start class article rated by WikiProject Medicine as low priority. However, when comparing cisgender women's health and cisgender men's health information on Wikipedia considering only Women's health and Men's health articles would be misleading. We also need to consider other articles. For example, although Thyroid disease was created in 2005, Thyroid disease in pregnancy was not created until 2010 and Thyroid disease in women was not created until 2017.

[75] See https://en.wikipedia.org/wiki/Wikipedia:Good_article_criteria

the next several months, William not only improved the article, he also nominated it for and guided it through the Good article review process. When I asked why he started editing Wikipedia in the first place, he said:

> *There were a slew articles that I came across. Well, they completely lacked any sort of feminist perspective. They were very much obviously male-written articles that I took to pieces. […] My work and my hobbies sort of both fed into my Wikipedia experience, but one has to be very careful because you can actually spend thousands and thousands of hours on Wikipedia at the expense of other priorities.*

At the time William devoted "thousands" of hours to improving *Women's health*, he had domain expertise, Wikipedia expertise, and time. But William had been editing Wikipedia since 2006, so—apart from a small edit in 2008—why did he not edit *Women's health* until 2016? During our interview, he said:

> *And so, I have to thank you for this. I decided, well, this [the* Women's health *article] should be a flagship article, and it should be one that ties in, you know, basically all of the articles involved in that scope, and they only way to find out what articles belong in that scope would be by writing an article and then seeing what links and whether those links are actually there.*

But why was it so easy for William (and many other editors) not to recognize *Women's health* as a "flagship article" until I mentioned it?

In summary, considering the life-history of the *Women's health* article on the English language Wikipedia enables us to think about what kinds of content receive editors' attention and what kinds of content are neglected. It also challenges assumptions about participant demographics as William, a cisgender man, was the editor who cared enough to make the article "good."

Discussion

In light of the life-histories above and the descriptions in Chapter 3 of what a Wikipedia article is and what it does, what do we gain from considering specific articles such as *Atrophic vaginitis*, *Vaginal cancer*, and *Women's health*? If vaginal cancer primarily affects postmenopausal women, survival rates are lower among African-Americans, and the disease is stigmatized due to its connection to HPV, multiple sex partners, smoking, and obesity, should we expect to see this content well-developed in Wikipedia? After all, as noted in prior research, Wikipedia has a noticeable gender gap in participation (see Appendix A), Wikipedians are unpaid volunteers, and page views of *Vaginal cancer* are low compared to, say, *Donald Trump* (a daily average of 81 views in the past 30 days compared to more than 45,000 in the same timeframe). But what if Wikipedia—as a sociotechnical system—perpetuates and produces neglect, not only mirroring but also magnifying existing health disparities?

Technical infrastructure

By infrastructure, researchers generally mean both the "technological substrate" (Bryant, Forte & Bruckman, 2005, p. 2) and the social norms and conventions of Wikipedia (see Ford & Wajcman, 2017). However, to tease apart the sociotechnical system that is Wikipedia, I have separated specific technologies (e.g., tools and features) from policies and the community in my discussion below. First, I discuss how the technical infrastructure of the site—as illustrated in a selection of tools—perpetuates the neglect of women's health information as evidenced in the object biographies above by directing both individual and collective attention away from this content.

Tools and attention

As discussed in Chapter 3, Wikipedia is built on wiki software, specifically MediaWiki, which enables it to be a collaboratively authored website users can modify directly from their web browsers (and, with more effort, from their mobile devices). What is unique about Wikipedia is that, while it is built on MediaWiki, it is so highly customized that the majority of the features and functionalities of Wikipedia are, as Geiger (2014) notes, "bespoke code." Some of these features and functionalities direct editors' *collective* attention to work that needs to be done. For example, ORES, a system created by the Scoring Platform team at the WMF, is used by about two dozen tools, most of them dedicated to combatting vandalism on Wikipedia. As noted in the object biography for *Vaginal cancer* above, Editor X set out to write content but quickly got "distracted" by the "instant gratification" of counter-vandalism. While necessary to maintaining Wikipedia, the tools created to combat vandalism may be so successful in directing collective attention that they direct it *away from* content creation.

We can imagine that a tool like a WikiProject has the potential to direct collective attention *toward* a particular content area, such as women's health, or a particular task, such as deletion sorting (Morgan et al., 2014). Matthew, an editor who helped to develop a suite of tools for WikiProjects (see Chapter 5), said:

> *We did research into people who have used WikiProjects, who have started WikiProjects—and we've identified a consistent pattern. It's usually one person who is dedicated in the project success; however, because it's a volunteer project, people eventually leave, and the project doesn't sustain itself. And there are very high costs of maintenance to run a WikiProject because, like I said, it's never received a lot of attention as a software feature. If you go to most WikiProjects, they're just pages of text. They're no more sophisticated than a Wikipedia article, even though these are processes, these are groups, and should be treated as such. And so, what my team set out to do is make it easier for people to run WikiProjects. I found a particular opportunity in creating WikiProjects for content areas that are underdeveloped in Wikipedia because there's a lot of interest in developing those content areas.*

However, as noted in Chapter 5, WikiProject Women's Health is, according to Eileen, "dead in the water." This may be because it overlaps with WikiProject Medicine, which is a much older and larger WikiProject, or because WikiProject Women's Health was created by established editors and, as other researchers have found, early contributions of "power users" may actually stall rather than bolster a WikiProject (Solomon & Walsh, 2014). Or it may be that a tool *alone* is not enough to direct collective attention.

There are also other kinds of tools on Wikipedia that direct *individual* attention. For example, many editors use watchlists: "a page which allows any logged-in user to keep a list of 'watched' pages and to generate a list of recent changes made to those pages (and their associated talk pages)."[76] As researchers (e.g., Viégas, Wattenberg & McKeon, 2007; McDonald, Gokham & Zachry, 2012) have noted, tools—

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[76] See https://en.wikipedia.org/wiki/Help:Watchlist

like watchlists or templates—enable *social translucence*: “a socio-technical term to describe how systems can facilitate understanding with regard to the actions of people in online environments” (McDonald, Gokham & Zachry, 2012). These tools often enable editors to monitor articles of interest (articles they *care* about) to ensure the articles are not vandalized, but this kind of monitoring can also enable territorial behaviors that deter participation from new editors (e.g., Kriplean et al., 2007; Thom-Santelli, Cosley & Gay, 2009) and, in some cases, from women (Menking & Erickson, 2015). For example, Eileen talked about how social translucence can enable “peeing on trees”:

> *So, as soon as I start working on an article that’s already been tagged, [Editor] shows up, I don’t know, within a day or two, goes over it, rewords it. It’s kind of like—okay, this is rude, but you can quote me if you want on this one. It’s kind of like—and it’s just him, it’s just him, it’s like no one else—it’s like he’s peeing on trees, okay? Okay, you know, like, “I have to know that you need to come after me and switch around two words.”*

This kind of behavior on Wikipedia can be an instance of *wikihounding*:

> The important component of hounding is disruption to another user’s own enjoyment of editing, or disruption to the project generally, for no constructive reason. Even if the individual edits themselves are not disruptive per se, “following another user around”, if done to cause distress, or if accompanied by tendentiousness, personal attacks, or other disruptive behavior, may become a very serious matter and could result in blocks and other editing restrictions.[77]

While the responsibility for reporting wikihounding rests on the shoulders of the editor being hounded and the available tools that can be used to direct individual attention to articles can also be used to facilitate harassment, tools for blocking these kinds of behaviors on Wikipedia currently do not exist, and we know that harassment has an impact on who edits Wikipedia (Menking, Erickson & Pratt, 2019).

Another (less potentially sinister) tool that directs individual editor’s attention is SuggestBot. Created by an academic researcher (see Cosley et al., 2007) and operated by a Foundation employee, this bot “is a computer program that tries to help Wikipedia contributors find articles to edit.”[78] While a promising tool for engaging editors in content creation and addressing topical areas that may be neglected, SuggestBot is unlikely to be used by new editors as it requires both awareness and set-up. For example, a user needs to first navigate to the page for SuggestBot, read the following, understand enough of the context to make a selection (i.e., know what a WikiProject or the Teahouse is), and then follow the instructions:

> To get a single set of suggestions:
>
> …based on articles you’ve edited, please follow the instructions at User:SuggestBot/Requests.
> …using WikiProjects you are interested in, go to the Teahouse’s SuggestBot page, click on Get suggestions, and follow the instructions.
> …based on a specific set of articles or categories of articles, see our instructions for that.
>
> You can also get suggestions posted periodically to your talk page (or another page of your choosing). How to do that is described here.[79]

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[77] See https://en.wikipedia.org/wiki/Wikipedia:Harassment#Wikihounding

[78] See https://en.wikipedia.org/wiki/User:SuggestBot

[79] See https://en.wikipedia.org/wiki/User:SuggestBot

Related to the potential of SuggestBot to direct attention toward neglected content is a study about misalignment between supply and demand on Wikipedia (Warncke-Wang et al., 2015). Using article pageview data, Warncke-Wang and his colleagues investigated the quality of popular articles and found "extensive misalignment between production and consumption" across four language Wikipedias, including the EN Wikipedia. They note that SuggestBot might be modified to "suggest […] articles for improvement, and also identify and suggest candidate sets of editors with the required range of topic and Wikipedia expertise, thus enabling efficient production of content in alignment with demand." While this idea is promising, particularly with regard to women's health content, the object biographies above raise questions about whether pageview data is the best measure of interest in a given topic. We might ask: Did *Vaginal cancer* have a daily average of 81 views in the past 30 days because readers are not interested in the topic or because Wikipedia's entry for it falls so low in search results due to the quality of the article?

In summary, we can imagine tools might be created to direct both individual and collective attention *toward* content that has been neglected. We can imagine tools might be created to reduce the impacts of systemic bias and prompt editors to reflect on the kinds of language and references they use. We can also imagine tools might be created that make it easier for editors who are harassed to report harassment and have some control over their interactions on-Wiki. But these tools do not exist, and this absence tells us something too about how Wikipedia's attention is collectively organized.

Policy

As noted in Chapter 3, Wikipedia is governed by five pillars, more than two dozen content and conduct policies, and hundreds of guidelines. Here, I want to draw the reader's attention to one pillar, *Neutral Point of View* (NPOV), and a related content policy, *Due weight.* Arguably, all of the five pillars and related content policies contribute to the production and neglect of women's health information on Wikipedia, but I have chosen to focus on these two given the object biographies above.

Neutral Point of View

Wikipedia is guided by five underlying principles called *the five pillars*—principles that inform and undergird the prevailing epistemic and social norms and practices for Wikipedia participation and contributions. The first draft of the five pillars was created on May 4, 2005. This draft describes the principles as "five unchangeable pillars that define Wikipedia's character." Several of the values expressed in the five pillars were articulated by Larry Sanger, who co-founded Wikipedia with Jimmy Wales, *before* Wikipedia (wikipedia.org) was established. For example, Sanger notes he's "fairly sure" one of the first policies he and Wales agreed upon was "a 'nonbias' or neutrality policy" (Sanger, 2005). In fact, the five pillars have changed very little since 2005.

The NPOV pillar reads:

> **Wikipedia is written from a neutral point of view.**
> We strive for articles that document and explain the major points of view, giving due weight with respect to their prominence in an impartial tone. We avoid advocacy and we characterize information and issues rather than debate them. In some areas there may be just one well-recognized point of view; in others, we describe multiple points of view, presenting each accurately and in context rather than as "the truth" or "the best view". All articles must strive for verifiable accuracy, citing reliable, authoritative sources, especially when the topic is controversial or is on living persons. Editors' personal experiences, interpretations, or opinions do not belong.

While some researchers argue NPOV "is affected by subjective interpretation and constant conflicts" (Matei & Dobrescu, 2011), others suggest Wikipedia's infrastructure—including policy—extends the "the epistemologies of previous male-dominated technoscientific projects" (Ford & Wajcman, 2017). In a paper currently under review, my colleague Jon Rosenberg and I argue NPOV needs to be re-envisioned for yet another reason: it presents objectivity as an end product rather than as a process negotiated by an epistemic community (Menking & Rosenberg, n.d.). We write:

> The upshot to this [focus on process] is whatever content we end up with at the end of this process, whatever we end up endorsing as the product of inquiry, is in no way neutral or objective itself. The best we can say is we have put the background beliefs and values that speak in favor of that theory to testing and criticism from the perspective of competing theories, background beliefs, and values. In other words, instead of grounding the "objectivity" of Wikipedia content in the neutrality or facticity of the content itself, the objectivity of Wikipedia—its distinctive epistemic integrity—should be understood in terms of the kind of community in which it was produced.

NPOV is, arguable, outdated in its view of knowledge production. Since Berger & Luckmann (1966), social scientists have recognized knowledge production as socially constructed and embedded in a particular time and place. To use Haraway's phrase, knowledge is *situated* (1988).

In the context of women's health information and the object biographies above, NPOV can be used as grounds to reject information related to the emotional and psychological aspects of a health condition. For example, an editor cited NPOV when he reverted William's use of the word "suffer" ("they also suffer more") in the *Women's health* article. Using NPOV in this way creates an environment that prioritizes clinician expertise over patient expertise. This may be particularly problematic when it comes to diseases and conditions impacted by health-related stigma.

Finally, NPOV's assertion that editor's interpretations "do not belong" is naïve; all text (e.g., primary, secondary, and tertiary sources) *must* be interpreted. (Some scholars argue all reading is interpretation; see Rabinowitz, 1998). We see an example of interpretation in the life-history of *Atrophic vaginitis* when, based on their reading of a medical article, an editor created a redirect conflating atrophic vaginitis with GSM.

Due weight

In the NPOV pillar, the phrase "due weight" links to a section of the *Wikipedia: Neutral point of view* page:

> Neutrality requires that each article or other page in the mainspace fairly represents all significant viewpoints that have been published by reliable sources, in proportion to the prominence of each viewpoint in the published, reliable sources. Giving due weight and avoiding giving undue weight means that articles should not give minority views or aspects as much of or as detailed a description as more widely held views or widely supported aspects. Generally, the views of tiny minorities should not be included at all, except perhaps in a "see also" to an article about those specific views. For example, the article on the Earth does not directly mention modern support for the flat Earth concept, the view of a distinct (and minuscule) minority; to do so would give undue weight to it.
>
> […]

> Wikipedia should not present a dispute as if a view held by a small minority is as significant as the majority view. Views that are held by a tiny minority should not be represented except in articles devoted to those views (such as Flat Earth). To give undue weight to the view of a significant minority, or to include that of a tiny minority, might be misleading as to the shape of the dispute. Wikipedia aims to present competing views in proportion to their representation in reliable sources on the subject. This applies not only to article text, but to images, wikilinks, external links, categories, and all other material as well.
>
> Paraphrased from Jimbo Wales' September 2003 post on the WikiEN-l mailing list:
>
> - If a viewpoint is in the majority, then it should be easy to substantiate it with reference to commonly accepted reference texts;
> - If a viewpoint is held by a significant minority, then it should be easy to name prominent adherents;
> - If a viewpoint is held by an extremely small minority, it does not belong on Wikipedia, regardless of whether it is true or you can prove it, except perhaps in some ancillary article.
>
> Keep in mind that, in determining proper weight, we consider a viewpoint's prevalence in reliable sources, not its prevalence among Wikipedia editors or the general public.[80]

Aside from the reference to people who believe the Earth is flat, *Due weight* does not define "minority views," "tiny minorities," "a distinct (and minuscule) minority," "small minority," "significant minority," or "the majority view." In the absence of a definition or operationalization of these terms, the implication in the text above is that the presence, prevalence, and "proportion" of a viewpoint in published reliable sources determines whether a specific viewpoint deserve due weight. The problem with this criterion is that reliable sources—academic, peer-reviewed publications, according to Wikipedia[81]—are generated by academia and academic publishing, academia and academic publishing often evidence gender (see West et al., 2013) and racial biases (e.g., Coleman, 2005; Sultana, 2018). Related to women's health information, researchers have found that evidence-based medical literature also exhibits these biases (e.g., Jagsi, et al., 2006; Holdcraft, 2007; Morgan et al., 2018).

In summary, when it comes to women's health, which we know is historically underfunded and understudied (see Chapter 2), principles like NPOV and policies like *Due weight* can perpetuate existing biases and, consequently, compound health disparities by favoring a viewpoint that is hegemonic rather than "neutral." And, while we could imagine a pillar like NPOV as aspirational rather than operational, we know based on prior research (e.g., Kriplean et al., 2007; Peake, 2015), that experienced editors often leverage the five pillars—particularly NPOV—to silence dissent.

Community

In Chapter 5, I argue that an editor's beliefs about gender rather than an editor's gender identity may be a more interesting factor to consider when interrogating relationships between participatory and content gaps. Below, I touch on participant demographics with particular attention to age and race-related gaps, which have been understudied on Wikipedia. This is not to suggest that these participatory gaps *alone* produce neglect, but rather to ask how—when combined with other factors such as those discussed above—they may impact the production and neglect of women's health information on the site.

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[80] See https://en.wikipedia.org/wiki/Wikipedia:Neutral_point_of_view#Due_and_undue_weight

[81] See https://en.wikipedia.org/wiki/Wikipedia:Verifiability#What_counts_as_a_reliable_source

The graying of Wikipedia

According to a 2011 survey of Wikipedians (*n*=4,930), 28% of editors are 40 years of age or older, and they make more edits than younger Wikipedians. According to a 2018 survey of Wikimedians, editors on the English language Wikipedia between the ages of 45-84 now make up 47% of the community. This shift in numbers may represent a "graying" of the editor community. However, according to the same 2018 survey, only 14% of all English language Wikipedia editors are women. So, while the editor community may be getting older, the gender gap is holding steady.[82]

How might the graying of Wikipedia impact women's health information on the site? We might imagine that as more Wikipedians age, they will have more lived experiences of age-related health conditions and pay more attention to age-related health information. This would be an interesting area for future study: Does coverage of content about health issues more prevalent among post-menopausal women improve as Wikipedians age? If not, why?

How white is Wikipedia?

As discussed in Chapter 3, the English language Wikipedia is the oldest and largest of all Wikipedias, and editors from all over the world—and from other language Wikipedias—often contribute. We also know that, while racial participatory gaps on Wikipedia are understudied and undertheorized, community initiatives (e.g., AfroCrowd, Black Lunch Table), popular press coverage about the recent controversy over the *Clarice Phelps* article (e.g., Jarvis, 2019), and even comments from long-time editors (see Chapter 3), indicate that participating in Wikipedia may require a certain degree of whiteness. (See my arguments in Chapter 5 about privilege and access to social and material capital.) Although this demographic skew has not yet been adequately researched, what might it mean for women's health information on Wikipedia if it does exist?

Research proves psychologically safe (e.g., Edmondson, 1999; Duhigg, 2016) diverse and inclusive teams are more productive (e.g., Hong & Page, 2004; Vasilescu et al., 2015) and more innovative (Díaz-García, González-Moreno & Sáez-Martínez, 2013). But, as my colleagues and I argue in a prior study (Menking, Erickson, Pratt, 2019), simply "adding women" (or members of any other marginalized group) will not "fix" the gaps on Wikipedia. Wikipedia, as a system and community, has been built to favor a specific kind of knowledge production, one that believes in and is concerned with matters of "fact" rather than matters of care.

Limitations

There are several limitations to this study. First, object biographies are not intended to be generalizable and if someone—a reader, a researcher, or an editor like Henry—wants to know if "Wikipedia's coverage of women's health is likely worse than Wikipedia's coverage, let's say, of men's health," the answer provided by this work may not be satisfactory. Second, this work is limited to the English language Wikipedia and limited to Wikipedia articles as digital objects. Finally, this work is not comprehensively comparative. By this I mean that, although I refer to specific articles about men's health, I neither engage in extensive comparisons nor do I consider a wide range of what could be

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[82] Assuming an even distribution of ages of women, at best only 7% of English language Wikipedians are menopausal or post-menopausal women. Yet even a number as "high" as 7% seems unlikely.

framed as women's health articles due to prevalence (i.e., breast cancer, migraines). This is an area for future work.

Conclusion

Women readers who seek online health information are likely to turn to Wikipedia (e.g., Laurent & Vickers, 2009; Fahy et al., 2014). But they may not know that the women's health information on the site is, in some instances, neglected and, in others, biased. We know socio-cultural factors (e.g., ageism, racism, sexism, stigma) impact the ways in which diseases and conditions impact marginalized groups, including women. By using object biography to identify factors contributing to the production and neglect of women's health information on Wikipedia, we are able to see it is not *only* socio-cultural factors but also the system itself that magnifies health disparities. From tools that direct individual and collection attention away from women's health content to policies like NPOV and *Due weight* that are leveraged to suppress already marginalized and/or stigmatized viewpoints to age and race-related participatory gaps in the community, Wikipedia *systematically* reproduces biases. As Wyatt and her colleagues write, "infrastructures and infrastructural relations are not neutral, and […] they sometimes serve to reinforce established social positions, even if not always intending to do so" (2016, p. 15).

In conclusion, I want to return to an excerpt from the Op-Ed entitled "Wikipedia mirrors the world's gender biases, it doesn't cause them" by Katherine Maher, the current Executive Director of the Foundation (see Chapters 2 and 5):

> Before Wikipedia points a finger that might rightly be pointed back at us, let me acknowledge that Wikipedia's shortcomings are absolutely real. Our contributors are majority Western and mostly male, and these gatekeepers apply their own judgment and prejudices. As a result, Wikipedia has dozens of articles about battleships and not nearly enough on poetry. We've got comprehensive coverage on college football but significantly less on African marathoners. At the same time, Wikipedia is by design a living, breathing thing—a collection of knowledge that many sources, in aggregate, say is worth knowing. It is therefore a reflection of the world's biases more than it is a cause of them.

Her use of the words "mirror" and "reflection" deserve explication. Although the allusion may not have been intentional on Maher's part, it is not accidental. As Andrew Brown writes in his brief history of encyclopedias (2011), encyclopedias have *always* been mirrors, but this does not mean their reflections are faithful:

> Mirrors can be deluding things: we *recognise* [author's emphasis] ourselves and our knowledge is reflected back to us. We are at home: even new things can fit easily into this frame. […] The encyclopaedia has to mirror something. (You? The world?) If we are to trust an encyclopaedia, the information in it must be findable elsewhere: a work of reference needs to reflect (and copy) other texts. […] The encyclopaedia was traditionally a mirror of the world (a *speculum*)—of how it was, of how it should be. (p. 105)

Brown goes on to write that that the encyclopedia was "also often a mirror for princes" (p. 105) and he points out earlier in his historical account that it was also a mirror for the Church; that is, it was a mirror for those in power. So, yes, Wikipedia continues this tradition of an encyclopedia by reflecting "the world's biases" including patriarchal and heteronormative views of women's bodies and sexism in medicine, but it does this not only because of the demographics of its contributors but also because it was *designed*—intentionally or not—to do so.

Chapter 7: Using Object Biographies to Understand the Reproduction of Scientific Knowledge about Women's Health in the Public Sphere

Introduction

Buzzfeed—an American Internet media, news, and entertainment company with a focus on digital media—often features articles that consist of curated hyperlinked lists of Wikipedia articles. One such article "21 Wikipedia Pages That Will Make It Impossible For You To Sleep" (Stopera, 2014) includes *Coffin birth*, a Wikipedia article about the postmortem expulsion of a fetus. Reading *Coffin birth* is not for the queasy or faint of heart:

> Coffin birth, also known as postmortem fetal extrusion, is the expulsion of a nonviable fetus through the vaginal opening of the decomposing body of a deceased pregnant woman as a result of the increasing pressure of intra-abdominal gases. This kind of postmortem delivery occurs very rarely during the decomposition of a body. The practice of chemical preservation, whereby chemical preservatives and disinfectant solutions are pumped into a body to replace natural body fluids (and the bacteria that reside therein), have made the occurrence of "coffin birth" so rare that the topic is rarely mentioned in international medical discourse.

I first read about coffin birth when I was selecting candidates for object biographies. I was curious as to why this article had been marked as relevant to women's health and why, since it was rated as being of "low importance" to WikiProject Women's Health, it had been developed into a Good article—a status achieved by only 1 in every 199 articles on the English language Wikipedia. Looking at the article's revision history, I realized the majority of the article had been written by one editor. Why did he care so much about coffin birth? At the same time, I became interested in another article that had also been marked as relevant to women's health, rated as "mid-importance" by WikiProject Women's Health, and developed into a Good article: *Abortion-breast cancer hypothesis*. Like *Coffin birth*, the majority of this article had been written by one editor. Both articles also evidenced staying power; they were created in 2004, only three years after Wikipedia's start. These two outliers fascinated me. Why were articles of such low importance—one about a rare post-mortem occurrence and the other about a politically charged hypothesis the majority of the medical community rejected in the early 2000s (see Stephenson, 2004)—so well-developed? Why had these two editors invested so much time and unpaid labor in these two articles? After conducting interviews with both editors and studying the history of both articles, I decided to include *Abortion-breast cancer* and *Coffin birth* in my selection of object biographies because, on the surface, they seemed to be such outliers. Additionally, they presented interesting questions about how scientific knowledge is reproduced in the kind of digital public sphere afforded by sociotechnical systems like Wikipedia.

In this chapter, I ask: *What can object biographies tell us about the reproduction of scientific knowledge related to women's health in public spheres like the English language Wikipedia?*

Related Work

There is a significant amount of work in STS about scientific knowledge production and reproduction (for example, work by social construction of technology (SCOT) scholars like Shapin & Schaffer, 1989) and a diverse body of work from political science to communication and media studies to CSCW about collaborative knowledge production in the virtual public sphere (Papacharissi, 2002) and on Wikipedia (e.g., Swarts, 2009; Niederer & Van Dijck, 2010; König, 2013; Bilić, 2015). Here, I focus on related work that is specifically about the reproduction of *scientific knowledge* on Wikipedia. (For a discussion of women's health in general and women's health information online, see Chapter 2; for a description of Wikipedia as a site of study, see Chapter 3.)

The reproduction of scientific knowledge on Wikipedia

Wikipedia, as an online encyclopedia that purports to be a site "anyone can edit," is well-positioned to be a virtual public sphere in which, theoretically, *anyone* can participate in the reproduction of scientific knowledge. However, as other scholars have noted (e.g., Lam et al., 2011; Morgan et al., 2013a; Menking & Erickson, 2015), Wikipedia presents several non-trivial barriers to participation, including but not limited to literacy, Internet access, some degree of technical knowledge, and a willingness to learn and abide by the communities' rules. The nature of Wikipedia's rules and policies also create a unique environment in which participants assume different roles as they participate in the reproduction of scientific knowledge. For example, in their comparative study about how knowledge about the Measles, Mumps, and Rubella (MMR) vaccine is collaboratively produced, re-used, and shared on Wikipedia, Baby Center, and Berkeley Parents Network, Hara & Sanfilippo (2016) found that, on Wikipedia, editors adopted a role that was uncommon on the other two sites: *judge*. According to Hara & Sanfilippo (2016) a *judge* is a person who demands and/or evaluates documentation (i.e., evidence) or justification for changes to content or process (p. 1595). Of the *judge* role the authors write:

> This role appeared to be more important in knowledge co-construction sites, as one-third of the participants in Wikipedia are coded as playing a judge role. When participants are socially constructing 'knowledge' online, someone needs to evaluate and make judgments about the quality of contributed content. (p. 1600)

In contrast, studying the Swedish language Wikipedia, Sundin (2011) suggests all Wikipedia editors assume the role of *janitor*. He compares scientific knowledge reproduction on Wikipedia to Latour's conceptualization of collaborative knowledge production in the scientific laboratory: "Fact construction is so much a collective process that an isolated person builds only dreams, claims and feelings, no facts" (Latour, 1987, p. 41). Here, Sundin argues that Wikipedians function as *janitors of knowledge* and reproduce "facts" on Wikipedia by abiding by policies (e.g., verifiability) and, thus, keep Wikipedia "stable" by recycling what has already been published.

Similarly, in their study of how knowledge about schizophrenia genetics is reproduced on Wikipedia, Wyatt and her colleagues (2016) describe how editors engage in *curatorial work*, using Wikipedia's rules and policies in addition to relying on hierarchy (i.e., anonymous users, editors, administrators) to negotiate what is and is not include (published scientific literature *vs.* lived experiences). However, when evidence is ambiguous or unavailable or editors disagree about what counts as evidence, controversy ensues. The authors write: "Wikipedia provides an *ad hoc* citation and curation of scientific resources, the selection of which is shaped by embedded hierarchies, protocols, expertise and access to literature" (p. 22).

Overall, prior work suggests the reproduction of scientific knowledge on Wikipedia is largely dependent upon policies, hierarchies of users, and the available scientific literature. The majority of these studies rely on document and/or content analysis (of article revisions and talk page discussions) and trace data (revision histories). One exception is Sundin's study (2011), but, although he engaged in ethnographic research (e.g., participant observation and interviews), he focuses on the Swedish language Wikipedia, which is much smaller and younger than the English language Wikipedia. Moreover, to date and to the best of my knowledge, there have not been any studies conducted about the reproduction of scientific knowledge related to women's health topics on Wikipedia. Therefore, this chapter builds on and extends prior work by using object biography to interrogate the reproduction of scientific knowledge about women's health (broadly construed) on the English language Wikipedia. Additionally, I employ a critical feminist lens with an eye to the participatory gender gap and tease apart notions of evidence and expertise.

Methods

Because the methods I have used here are similar to the methods used in Chapter 6, I have provided only a brief overview of methods below. Please see Chapters 4 and 6 for more details.

Ethical considerations

I obtained Institutional Review Board (IRB) approval from the University of Washington before recruiting interviewees for this study. I provided all interviewees with study information and asked they (1) acknowledge they were 18 years of age or older and (2) provide either verbal or written consent. I offered interviewees compensation in the form of Amazon gift cards ($25 per physical card) funded by the University of Washington Information School's doctoral dissertation grant. I also invited interviewees to review their transcripts. Please see Chapter 4 for more detailed information about ethical considerations.

Interviews

Recruitment and sampling

To recruit interview participants, I reached out to each editor via Wikipedia's email (see Appendix C). I chose not to use the You've Got Mail template on user talk pages because I did not want to draw attention to potential interviewees' participation given how small the editing community is. I used purposive sampling because I wanted to speak to editors who had contributed to articles I had selected as object biography candidates.

Data collection

I conducted both interviews in English via Skype. I audio-recorded the interviews and took handwritten notes. Both interviews lasted for more than two hours and resulted in multiple email exchanges post-interview. I transcribed both interviews verbatim and then destroyed the audio recordings.

Data analysis

After transcription, I imported all interview transcripts and interview notes into NVivo, a qualitative data analysis software tool, where I conducted *in vivo* coding (Manning, 2017). Because the interview data was collected iteratively and in tandem with other data (e.g., article and talk page data, trace data), I used open coding and memoing to identify emerging themes across data sources (e.g., Miles & Huberman, 1984; Strauss & Corbin, 1998).

Object biography

Please see Chapters 4 and 6 for a detailed explanation of why and how I adapted the method of object biography for this dissertation work as well as how I handled sampling, data collection, and data analysis.

Sampling

Please see Chapters 4 and 6 for more information about how I selected articles for object biography candidacy. Relevant to this chapter, it is most important to know I selected *Abortion-breast cancer hypothesis* and *Coffin birth* not only because they met the requirements for object biography candidacy but also because, on the surface, they seemed to be interesting outliers. However, upon closer inspection, the life-histories of these two articles prompted me to ask questions about how scientific knowledge about women’s health is reproduced in the public sphere. Finally, the life-histories of these two articles are particularly interesting as both were created as “gifts” and yet one has become a commodity (e.g., the opening illustration about how Buzzfeed uses Wikipedia articles; see Kopytoff, 1986).

Data collection

For each article, I collected article revision histories, talk page discussions, and trace data. To do this, I used a Python script to scrape Wikipedia, collecting all revisions and logs for each article to create two CSV files for each article: revision data and log data. I also manually inspected each revision for each article and took screenshots of versions that evidenced significant content change (i.e., the inclusion of a new paragraph), introduced new references or resources, or images. I read all talk page discussions, took screenshots of page information data, and downloaded page view data.

Data analysis

All article data was analyzed in a non-linear and iterative fashion. For example, as I coded the log and revision data I downloaded into CSV files, noting different kinds of edits, including acts of vandalism (VAN) and subsequent reversions (REVERT), applications of categories (CAT) and tags (TAG), and content creation (CC), I also manually inspected revision histories on Wikipedia. During this time, I was also conducting axial coding of a subset of interview data and writing memos to identify emerging themes. The focus of my data analysis for these two articles was largely driven by interview data.

Findings

In the sections below, I draw from interview data, article data (including talk pages and revision histories) and trace data to tell the life-history of *Abortion-breast cancer hypothesis* and *Coffin birth*. In telling these stories, I ask: *What is the article? What does it do? When did it come into being? How? Who was involved in creating it? What did they want it to be? What do other people want it to be? How does the article serve as a boundary object? How has it been commodified? What does it want to be? What can it tell us about the reproduction of scientific knowledge related to women's health on Wikipedia?*

Abortion-breast cancer hypothesis

The potential link between an induced abortion (*vs.* a miscarriage) and an increase in the risk of breast cancer is most commonly referred to as the *abortion-breast cancer link* (or ABC link). Though the mainstream medical community has overwhelmingly agreed that the "scientific evidence does not support the notion that abortion of any kind raises the risk of breast cancer or any other type of cancer" ("Abortion and breast cancer," n.d.) some researchers (Brind, 2017) and many anti-abortion activists continue to advance this hypothesis. Indeed, a recent *New York Times* opinion piece suggests the "abortion wars have become a fight over science" rather than constitutional rights (Ziegler, 2019). According to Patricia Jasen (2005), a historian of medicine, this "fight over science" has been raging for decades. Jasen details how research about a possible link between abortion and breast cancer began "in earnest" in the 1980s, with epidemiologists, perhaps without realizing it, being drawn into an international and highly politicized debate. She writes:

> The international debate over whether abortion increases breast cancer risk, which has been the subject of many studies and much heated controversy in recent decades, became so intensely politicized in the United States that it serves as a particularly stark illustration of how elusive the quest for scientific certainty can be.

In the following sections, I tell the life-history of the *Abortion-breast cancer hypothesis* article, beginning with its birth in 2004. In the vignettes that follow, I am particularly interested in how editors who are not medical experts (e.g., oncologists, epidemiologists) and who do not have formal training in related fields access and interpret evidence, arguing for "scientific certainty." I am also interested in how they approach the topic with regard to how they address (or do not address) the potential of stigmatizing women who have had abortions and the emotional nature of the content.

The birth of an article

The *Abortion-breast cancer hypothesis* article was created in 2004, approximately three years after the start of the English language Wikipedia. Unlike *Atrophic vaginitis, Vaginal cancer, Women's health,* and *Coffin birth,* the *Abortion-breast cancer hypothesis* article was not created as a stub first. Rather it was created as a full article with eight subsections, including "Scientific Studies," "NCI Workshop," and "Anti-Abortion Bias." This is evidence that the editor who created the article (hereafter referred to as Editor A) either drafted the article in what is known as an editor's *sandbox*—a space to experiment with the process of editing—or off-Wiki. Why would an editor do this? According to Eileen (see Chapters 5 and 6), she sometimes edits off-Wiki to avoid other editors' surveillance because, while a sandbox is a space to experiment, it is not a private or protected space:

> *I would go to my sandbox, and I would have seen that thirty people had looked at what I was writing, and that creeped me out a little bit. So, I would—I'd make that page disappear and work on it offline. And get it to where I wanted it to be. You know what? I should not be that—I should not be that—how do I say it? I should not be that interesting. […] I just think it's so weird. So, I don't like working in my sandbox. […] Let's say you create something in your sandbox, you take it off, you put it in Word, you delete your sandbox page or draft page or whatever it is—you can copy and paste whatever it is that you've been working on in Word into a sandbox and hit Preview. And you can see what it's going to look like without actually making an edit. I do that a lot.*

Like Eileen, Editor A may have created the first version of *Abortion-breast cancer hypothesis* in his sandbox or off-Wiki to avoid drawing attention to his work; it is difficult to know without asking him.[83] But, given the controversial nature of the topic and the fact that the draft of the article does not appear in the revision history for any of Editor A's sandboxes, we can speculate that *Abortion-breast cancer hypothesis* was born off-Wiki.

The life of an article…and an editor

As of the writing of this chapter, in the last 15 years, *Abortion-breast cancer hypothesis* has been edited 1,682 times by 247 editors as of the writing of this chapter. The article talk page has been edited 1,464 times by 103 editors. Karsten and two other editors (hereafter referred to as Editors B and C) have dominated both the article edit history and the article talk page history. Editing activity on the article peaked in 2007, when the editing community began to shrink (Suh et al., 2009). The article was first nominated for the Good article review process in August 2006 and was finally listed as a Good article in July 2008. Today, the article is marked as being of interest to the following WikiProjects: WikiProject Medicine, WikiProject Alternative Views, WikiProject Skepticism, WikiProject Conservatism, WikiProject Abortion (new defunct), and WikiProject Women's Health. Only WikiProject Skepticism, a project "focused on scientific skepticism and clarifying the distinction between science and pseudoscience," categorizes the article as being of high-importance.[84]

Because Karsten has been so involved in the life of *Abortion-breast cancer hypothesis*, it is difficult to discuss the life-history of the article without discussing who Karsten is, what he wanted the article to be, and how he tried to shape it. Given our conversation, which lasted for more than two hours and was followed by several email exchanges, it was clear to me that Karsten was passionate about the topic. A self-proclaimed "information addict," Karsten would want me to begin with this: despite what readers might assume given his work on *Abortion-breast cancer hypothesis*, he is pro-choice. In fact, Karsten told me he became interested in the topic when he was editing the *Abortion* article:

> *One of the things I was looking at just as I started to engage Wikipedia at the very beginning was […] the very first sentence of the Abortion article, and that was a challenge to me. That was*

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[83] Because Editor A identifies as a man on his user page, I have used masculine pronouns.

[84] See https://en.wikipedia.org/wiki/Wikipedia:WikiProject_Skepticism

> *something I really wanted to get right, get the balance right, and that really drove me to engage with the topic in a meaningful way. So, I really wanted to get that first sentence right in the Abortion article and, for a while, it was the one that was a team effort, but I had led the effort on the talk page to make the sentence. The sentence involved the word "death," and that rubbed a lot of people the wrong way, and I understood why, and to this day I appreciate why. But my counter to that, I was like, "Well, Encarta uses the word death." And from my perspective—and some people were so adamant that I was anti-choice because I had the word "death" in there. And they said, "Well, even if you're not anti-choice, you've been hoodwinked. You've been hoodwinked by the pro-lifers. Bad on you for giving into them." And I said, "I didn't really give into them. I listened to them, and I thought to myself, 'Regardless of which way you slice it, regardless of where you are on the spectrum of abortion, it's an emotional topic'." And I felt it was relevant to have an emotionally evocative word. One word. In a sentence that is otherwise clinical, dry, emotionally detached by design. And I thought that was appropriate. So, it stayed for a while. And that was one of my achievements, and I was very proud of it. And I leveraged my administrative abilities to keep it there for the longest time possible […]*

We learn several things about Karsten and the kind of editor he is here. First, we learn that attention to detail is important to him; he wanted to get the "very first sentence" of the *Abortion* article "right." Second, we learn that, although he is pro-choice and ostensibly reproducing scientific knowledge, he wanted to use "an emotionally evocative word" and appealed to exogenous sources like Encarta, a digital encyclopedia published by Microsoft from 1993-2009, to defend his choice of diction. Finally, we learn that Karsten was an administrator and "leveraged" his position and related permissions to keep "death" in the first sentence of the *Abortion* article for as long as possible.

By Karsten's on admission, he is much less involved in Wikipedia now than he was when he was working on the *Abortion* and *Abortion-breast cancer hypothesis* articles. He will sometimes go months without editing and, although he says he has 122 pages—including *Abortion-breast cancer hypothesis*—on his watchlist, he has disabled notifications from Wikipedia. He told me he mostly engages when he receives explicit requests on his talk page or emails and that, even if he returns to edit, "the enthusiasm evaporates, and you move back to real life, to the real world." When I asked him why he had devoted so much time and attention to *Abortion-breast cancer hypothesis* over more than a decade, he replied:

> *I found purpose in trying to engage in these wicked problems, and so that gave me some motivation to continue, to keep on going, keep on going. And I, to this day, am still engaged in the topic despite my lack of passion overall [for Wikipedia] because I think for the ABC hypothesis [Abortion-breast cancer hypothesis], which is a term that I actually invented. I will take the credit—the good and the bad—for that. Because I think it's probably one of my few opportunities in life to actually contribute back to humanity. Pretty much.*

Accessing and evaluating evidence

When I spoke to Karsten, he spent a great deal of time describing in detail how he accessed and evaluated evidence for the article. Sometimes this meant he would physically visit a local university library and make photocopies of relevant studies:

> *And then that meant—that means I'd be going to a local university and photo-copying studies. I'd be doing the research. Photocopying the primary sources right at the library, taking them out*

> *of the journals, and looking at the source material myself. […] I had to look up a lot of terms, and I had to educate myself a little bit just to follow what they're talking about.*

As Karsten notes above, he was accessing "primary sources" and then doing supplementary reading so that he could understand the primary sources as he holds a four-year university degree in computer science and not a field directly related to medicine. This is notable for three reasons: (1) Karsten could prioritize his time in such a way as to visit the local university library and do this in-depth research; (2) relatedly, he had the skills and capital (both social and material) necessary to do this in-depth research; and, finally, he chose to access primary sources when, as an experienced editor, he knows Wikipedia policies favor secondary and tertiary sources over primary sources. For example, WP:Primary[85] includes the following (emphasis in original text):

> […] Primary sources may or may not be independent sources. An account of a traffic incident written by a witness is a primary source of information about the event; similarly, a scientific paper documenting a new experiment conducted by the author is a primary source on the outcome of that experiment. […]
>
> ***Policy***: Unless restricted by another policy, primary sources that have been reputably published may be used in Wikipedia, but only with care, because it is easy to misuse them. Any interpretation of primary source material requires a reliable secondary source for that interpretation. A primary source may only be used on Wikipedia to make straightforward, descriptive statements of facts that can be verified by any educated person with access to the primary source but without further, specialized knowledge. […]
>
> - **Do not** analyze, evaluate, interpret, or synthesize material found in a primary source yourself; instead, refer to reliable secondary sources that do so.
> - **Do not** base an entire article on primary sources, and be cautious about basing large passages on them.
> - **Do not** add unsourced material from your personal experience, because that would make Wikipedia a primary source of that material. […]

However, despite this policy and Karsten's experience as an editor and administrator, he devoted "months" to analyzing, evaluating, interpreting, and synthesizing primary materials. He also devoted a significant amount of time ("we're talking months") to understanding a meta-analysis—a source which is commonly used on Wikipedia and adheres to policy constraints—first-authored by a controversial figure in the debate about abortion and breast cancer, a professor in human biology and endocrinology at Baruch College of the City University of New York:

> Karsten: *So, I went through the studies. I went through just to see if there were further holes in the consensus view. The first one that I came across was that Brind was a hack. That he really didn't fundamentally know what he was talking about. That he got the fundamentals wrong. And when I came across that discrepancy between Brind and Joyce, I realized, and I then scrutinized him a lot. Some of the stuff I disagreed with, especially in the interpretation of the epidemiological results because you can argue it either way when you come down to it, when you're talking about thousands of people, and statistical analysis done this way, and statistical analysis done that way, and it's too technical for me, and I just don't have the competence for that. But when… but on the basic scientific principles, he was spot on. And as he should be because he's—do you know what he specializes in?*
>
> Amanda: *No, I've only looked at the references in the article. I haven't looked him up.*

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[85] See https://en.wikipedia.org/wiki/Wikipedia:No_original_research#Primary,_secondary_and_tertiary_sources

> Karsten: *Yeah, he's an endocrinologist, which is a specialist in hormones. And so… unfortunately, it's a fit for the topic. Let's see here… So, when I went through the articles, I got all the articles together, reviewed them all—we're talking months of just going through them […]*

Karsten became so engaged in his research for the *Abortion-breast cancer hypothesis* article that he contacted another researcher who, like Brind, reported an increased risk of breast cancer in women who had induced abortions (*vs*. miscarriages). This researcher, now an emeritus member of the Fred Hutchinson Cancer Researcher Center and emeritus professor of epidemiology at the University of Washington, warned against reaching "a firm conclusion" at the time of her first publication (Jasen, 2005) and would release a study two years later, claiming "there was no excess risk of breast cancer associated with induced abortion among parous women" (Daling et al., 1996). Karsten said:

> *But I called her—I didn't want to hassle her. […] I called her just to say, just to ask her, "Was that a valid quote?" You know? And when I called her, she didn't confirm or deny it. But I definitely got the sense of wariness from her on the topic, and I felt she had been beaten down professionally, maybe in every way possible, and she was just done with it—kind of like how I'm done with Wikipedia—and she just didn't want to engage with it in a meaningful way.*

As recently as 2017, editors discussed whether work by Brind and Daling should be included at all with one editor arguing they are not reliable sources and, at the same time, accusing Karsten of putting too much of himself in the article. Indeed, as the ability to access and evaluate evidence has been central not only to the life-history of the *Abortion-breast cancer hypothesis* article on Wikipedia, but also of the debate itself. As Jasen (2005), writes, "it serves as a particularly stark illustration of how elusive the quest for scientific certainty can be." How, then, can we expect Wikipedians—unpaid volunteers who may lack formal training in research, clinical trials, epidemiology, and statistics—to reproduce this kind of scientific knowledge? I return to this question in the Discussion section below.

Rejected vs. unsupported

The talk page for the *Abortion-breast cancer hypothesis* article has generated a significant amount of activity with 125 original posts, 11 of which have more than 20 replies each. After the Good article peer review update (with an estimated 59 replies), the post with the most responses is entitled "Rejected vs. unsupported" with an estimated 47 replies. In summary, this discussion revolved around whether the article should position the hypothesis about the connection between abortion and breast cancer as *rejected* or *unsupported*. Karsten and two other editors (Editors B and C) dominated this discussion. Responding to Karsten and Editor C, Editor B writes:

> I think you've hit the crux of the matter. Prions were settled in the 1980's, and if Wikipedia had existed, I would expect it to have said that prions were harmless. That's Wikipedia's role: to summarize what other reliable sources have said, not to be ahead of the curve and out-analyze them. Then, when the scientific consensus changed to incorporate prions as a cause of disease - then Wikipedia would reflect that new understanding. Scientific understanding may change - in fact, it definitely will. Wikipedia, though, should lag suitably behind changes in the scientific consensus rather than trying to anticipate them. "Rejected by the scientific community" is just a statement of fact. Tomorrow it could be un-rejected - if the WHO comes out with a statement that suddenly supports ABC, then we'll update the page. But for today, it's been rejected.

In the excerpt from one of Editor B's comments above, he notes that scientific consensus *changes* over time, and that it is the role of Wikipedia to "lag suitably behind changes in the scientific consensus" rather than trying to produce (*vs*. reproduce) scientific knowledge. Although Karsten and Editor C did not disagree with Editor B's assessment of how science progresses or the role of Wikipedia, they both raised concerns about how scientific knowledge is produced in specific social and political contexts. In particular, Karsten and Editor C noted that the National Cancer Institute (NCI) was under political attack due to push back from Brind and his supporters as well as pressure from the United States Congress. In response, Editor B writes:

> The only documented "political" aspect of the NCI workshop is that it was a response to Bush Administration efforts to play up a supposed ABC link. No reputable source, other than perhaps Brind if you consider him as such, has alleged that the NCI's conclusions were politicized - and Brind gets more than enough airtime in this article. As to "real science", that's a bit judgemental [*sic*]. After all, WP:V and WP:OR actually suggest that we should base the article on expert interpretations of the primary data (such as the NCI panel's conclusions), rather than relying on our own personal parsing of the primary data.

The "NCI workshop" Editor B refers to here was a workshop called the Early Reproductive Events and Breast Cancer Workshop convened by the NCI in February 2003 to review existing research about the supposed ABC link to determine whether there was a relationship between breast cancer and abortions (both induced and spontaneous). More than 100 of the world's leading experts in the field and related domains (e.g., epidemiologists, clinicians, breast cancer advocates) attended, including researchers like Daling who had published work suggesting there was a link between breast cancer and abortion (e.g., Jasen, 2005, "Abortion, miscarriage," n.d.). The workshop attendees reached consensus that induced abortion was "not associated with an increase in breast cancer risk" ("Abortion, miscarriage," n.d.). As Editor B notes, linking to policies about verifiability (WP:V) and no original research (WP:OR), Wikipedia editors are tasked with *reproducing* what experts have produced, regardless of whether they agree with the experts or not. Karsten, however, continued to disagree, saying the evidence—not the experts—should be "king".

Today, as of the writing of this chapter (July 2019), the lead paragraph of the article reads (emphasis added):

> The abortion–breast cancer hypothesis posits that having an induced abortion can increase the risk of getting breast cancer. This hypothesis is at odds with mainstream scientific opinion and is **rejected** by major medical professional organizations. In early pregnancy, hormone levels increase, leading to breast growth. The hypothesis proposes that if this process is **altered** by an abortion, then more immature cells could be left behind, and that these immature cells could increase the risk of breast cancer over time.

Editor D, editing for only two years, made this change, replacing *contradicted* with *rejected* and *interrupted* with *altered* in December 2018. So far, Karsten, Editor B, and Editor C have let this edit stand.

Laying blame

As I discussed in Chapter 4 when defining stigma and again in Chapter 6 when addressing health-related stigma, certain health conditions and diseases are more stigmatized than others because the patient is perceived as being culpable. However, as Broom notes below, women are often perceived as culpable *regardless* of the condition or disease:

> The notion of women's essentially diseased nature appears in explanations for breast cancer, both medical and popular (Lupton, 1994). The representation of cancer as uncontrolled cell division (Stacey, 1997) carries feminine implications since unbridled reproduction is a decidedly female transgression, and the implications are amplified in the case of a female cancer. […] The debate surrounding abortion as a possible 'risk factor' for breast cancer is another illustration of interest in the sickening potential of women's refusal to concede authority over their child bearing. Even the age at menarche and menopause has been proposed as potentially influential. I do not argue that none of these factors could be relevant to the apparently rising incidence; my point is that the focus is fixed on women and our behaviour. (Broom, 2001, p. 258)

In the case of the debate about a possible relationship between abortion and breast cancer, because abortion is a highly politicized and stigmatized procedure many people consider immoral, a woman who has had an abortion and then has breast cancer may perceived as culpable for her illness. And even if women are not openly blamed, they may experience feelings of shame and stigma which prevent them from disclosing their abortions. For example, one systematic review of studies about abortion and stigma found women experience fear of social-judgement, self-judgement, and feelings of secrecy, even in countries where abortion has been legalized (Hanschmidt et al., 2016). As Broom continues, this kind of framing—of laying blame on women and their behaviors—neglects other factors like environmental pollution and ignores the relatively low survival rates for women of color with breast cancer.

When I asked Karsten whether he thought about a woman who has had an abortion or a woman who has had an abortion and now has breast cancer reading this article, he replied:

> *Frequently. Not… Hmm. Maybe it was 50% me thinking in those terms and 50% from the discussion? Or maybe it was like two-thirds discussion and one-thirds myself, but, you know, in the discussion, people would be like, "You can't say this, you can't say that. You know, this is like dealing with a real, serious topic." And I'm just like, "I appreciate that, but I was like: The science matters." They'd be like, "Science does matter, but so does people's perception of what could be a problem for them."[…] It did come up frequently in the early stages, but then as I got digging into it, I would tend to fall back on what the science—I'm going to do the best I can to reflect the science, and if that upsets some people, that's unfortunate, but that can't be helped. That might be how I would eventually fall back on to it because some of the things that I would have written in the discussion, especially the talk page of the article, maybe I would regret—whether it was the specific person I wrote to or within the broader context of women. But I felt like I was fighting a losing battle. I always felt like I was under siege, and, I mean, I was. I was. I was the only guy really trying to give the topic fair shake from my perspective, and everyone else was dismissive.*

Karsten's response is striking given his insistence that the "very first sentence" of the *Abortion* article include "an emotionally evocative word" like *death*. It is also striking because Karsten felt "under siege" and as though he was "the only guy" trying to craft an article that was true to "the science," which, in his mind, was the evidence rather than the experts. When I pushed Karsten asking him whether, after his years of research and writing, he believed there was a link between induced abortions and breast cancer, he said:

> *The epidemiologists are paternalistic to a certain degree […] a lot of male scientists were just like, "Well, you know, this is so small that we don't need to worry their little heads about that*

> *because they won't be able to—we can't be sure how it will be interpreted either by the journalists or by the general public, and through that filter of journalists, by women. So, you know what? We might as well just skip it." It might not be paternalistic, but they don't want it to get away from them. You know? They don't want it to cause undue harm, and whether that comes from a sexist subconscious or a general concern for women, in general—and maybe a lot of these researchers are saying, "If I'm talking to my mother or I'm talking to my sister, do I tell them this? I'm not sure if I do." I hope in my hopes of my hopes that the ones who know what they're doing and who are really informed about this topic will say, "I will tell my sister. I will tell my relative if they are considering getting an abortion, to get one as quickly as possible."*

Karsten expressed a strong desire for women to have the information they need to make informed choices about their health. Ironically, this "woman-centered" rhetoric is the same used by anti-abortion activists and researchers who, since the 1980s, have argued in support of the evidence of the ABC link (Jasen, 2005).

Abortion-breast cancer hypothesis, 2019

Today, the *Abortion-breast cancer hypothesis* article has reached Good article status and, with this status, a degree of stability. Although it does not appear on the first page of Internet search results for "abortion breast cancer," it does appear as the third result when I perform a similar search: "abortion breast cancer hypothesis." On Wikipedia, the subject seems to be decided; the hypothesis has been rejected by the mainstream medical community, and the majority of editors working on *Abortion breast-cancer hypothesis* agree with this framing. Off-Wiki, however, the debates continue. Most recently, Wendy Vitter, a judge nominated by Donald Trump and confirmed by the United States Senate to serve on the United States District Court for the Eastern District of Louisiana, reportedly believes that abortion causes breast cancer (Levin, 2019), abortion counseling in some states still includes notifying women of the presumed link between the procedure and breast cancer (Woodcock, 2011), websites for crisis pregnancy centers continue to declare a link between abortion and breast cancer (Bryant et al., 2014), and over two-thirds of women who have had a first-trimester abortion overestimate the health risks, including increased risks of breast cancer (Littman et al., 2014).

Coffin birth

As noted in the Introduction section above, I selected *Coffin birth* because it puzzled me. I was curious as to why compared to an article like, say, *Vaginal cancer*, it been marked as relevant to women's health and developed into a Good article. Josh, who was finishing his Ph.D. in Anthropology when we talked, did not create *Coffin birth*. However, he had committed hours to improving the article because the topic overlapped with his master's thesis in which, among other things, he "examined the skeletal remains from two archeology sites, and […] made the argument that in one case there was a skeleton of an adult female and a skeleton of a fetus." What became apparent as I coded and analyzed article data and the transcript of our conversation was that *Coffin birth* was an excellent example of how Wikipedians edit according to their interests and expertise and, consequently, how scientific knowledge is reproduced in the public sphere. What also became apparent was that the article was a fascinating example of how Wikipedia's content has become integrated into today's information ecosystems. In the sections below, I tell the life-history of *Coffin birth* in a series of vignettes, beginning with the article's birth in 2004.

The birth of an article

Like the *Abortion-breast cancer hypothesis* article, *Coffin birth* was also created in 2004. The article's creator (hereafter referred to as Editor 1), wrote:

> Coffin birth is the explusion [*sic*] of a fetus from the decomposing uterus of its dead mother as a result of the buildup of gases in the parent's decaying body. This kind of postmortem delivery is rare and requires the mother's body to be left unattended for some time.

Editor 1, who has a "This user is female" userbox on her user page, marked the article as a stub, included "graphic/explicit definition, stay away if squeamish" in her edit summary, and then never edited the article again though she has been active on Wikipedia as recently as 2018. According to her revision history, Editor 1 was most active in 2004 with more than 23,000 edits that year. In fact, in 2004, she created nearly a thousand new articles on Wikipedia across a wide range of subjects, from geography to biographies to entertainment to health-related topics. Without asking her, we cannot know what Editor 1's motivations were for creating *Coffin birth*, but—given her activity at the time and her edit summary—we can deduce that she was (1) actively creating missing content when and where she recognized gaps, and (2) recognized the potential emotional impact of *Coffin birth* on the reader.

The Laci Peterson case and a question about audience

Laci Peterson became the subject of a highly publicized murder case after she went missing during her eighth month of pregnancy and both her body and the body of her prenatal son were found several months later in a marshy area of the San Francisco Bay. Peterson's case is relevant to *Coffin birth* because, according to the article's revision history, talk page discussions, and my interview with Josh, the discovery of Peterson's prenatal son, Conner, and the media's depiction of the case brought the term "coffin birth" to the public's attention. As one editor noted in their 2004 edit summary: "Added mention of the Laci Peterson case, since that is responsible for introducing this term to the modern public." However, as Josh explained when we spoke, while the media's reports of the Peterson case may have brought coffin birth to the attention of the "modern public," it was *not* a case of coffin birth at all:

> Josh: *Even medical textbooks quit talking about it by the 1950s, I think. Because of embalming, there weren't any actual cases to be seen. So, the only documented cases before these forensic articles are, like, before the 1800s. [...] Also, the Laci Peterson case, I want to say late 1990s, it was the San Francisco case, the guy who killed his pregnant wife—*
>
> Amanda: *Yes, I remember that.*
>
> Josh: *Yeah, so when her body washed up on shore, the fetus washed up separately. So, a journalist wrote, This could be a case of coffin birth [...] and it was reported in dramatic language. "The cold depths of the unforgiving sea…" [...] But it turns out it wasn't. Just in the normal course of decomposition, the body—the skin ruptured—the abdominal skin ruptured, and just ordinary sea water washed the fetus out of there, and so it become separate. They were able to tell that forensically because—oh, I forget. I think the—I think they could see that the cervix hadn't been breached.*

As Josh and I continued our conversation, I asked him how he envisioned his audience for *Coffin birth*. He replied:

> *When I wrote it, I guess I did have an eye towards anthropologists because those are the books and sources I'm most familiar with. I think the guy who reviewed the article for Good article status, he asked for more clarification on the medical side of it, and I did have to go hunting for a medical textbook to find when coffin birth was talked about in the medical sense and when did American medical textbooks quit talking about it. But, yeah, I think I did have an eye toward archeologists and anthropologists.*

Although Josh may have envisioned his audience as archeologists and anthropologists—members of the communities in which he has studied and currently practices—as discussed in Chapter 5, Wikipedia's audience is, quite literally, the world. What is interesting about *Coffin birth* and the question of audience is, as Josh notes, "medical textbooks quit talking about it by the 1950s." That is, with advances in embalming, the topic was no longer relevant to the medical community; it became the domain of another discipline, another form of expertise. And, while the "modern public" may not have a fascination with archeologists and anthropologists, it does—and has for some time—have a fascination with forensics, making corpses "pop culture's new star[s]" (Foltyn, 2008, p. 154). Laci Peterson's case, which resulted in several television series, a handful of books, and a Netflix movie, provided two corpses for voyeurism.[86] And, as Josh noted both in his interview and his edits, medical examiners—whose expertise generally does not include forensic anthropology—speculated about the condition of the corpses, and the media reported this in "dramatic language" which, perhaps, led to confusion among early editors of the article and, ironically, drew readers to it. In this way, *Coffin birth* serves as an interesting boundary object that has passed from the domain of medical expertise to mortuary science to archeology and forensic anthropology and yet still has enough macabre appeal to interest a range of audiences.

Tagged

One of the first questions I asked myself about the *Coffin birth* article was, "How is the relevant to women's health? Why was it marked as relevant to WikiProject Women's Health?" Josh had some of the same questions. He said:

> *Aside from what's on the talk page, I don't think I've had to—I don't think I've talked about it on any other project page. It's on the front page of WikiProject Death, and other than that, one guy on a talk page—I think his name is [name of Wikipedian], he didn't even get past the first sentence. He thought it was post-mortem caesarian section, which just shows you again it's not a major topic in medicine. So, no. Nobody has really approached me about it, and whether it's talked about in other projects, I really have no idea.*

Coffin birth has been tagged as relevant to WikiProject Medicine (in 2007), WikiProject Death (in 2010), WikiProject Archaeology (in 2011), and WikiProject Women's Health. According to the revision history of the article talk page, *Coffin birth* was tagged by a member of WikiProject Women's Health in July 2015. When I asked Josh about this, he replied:

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[86] There is another study here about how society values the bodies of pregnant white women in ways that it does not value other bodies.

> *I didn't even know it was a part of WikiProject Women's health. I'm a little surprised by that—not surprised that it's included. I mean, the project members in any project can get pretty tangential in their inclusiveness and their enthusiasm, I guess you could say, to include everything. It's kind of a weird topic. It's difficult to know where to place it. I mean, obviously WikiProject Death applies […] When it comes to women's health, I guess, women's issues, I guess women's health is as close as any, except women's history, but that's kind of broad and really inclusive.*

As discussed in Chapter 5, defining women's health is a complicated task with both practical and ontological consequences. Without speaking to the WikiProject Women's Health member who tagged *Coffin birth* as relevant to the project, it is difficult to assume motivation; however, given the article's revision history, we do know the categorization of the topic has proven challenging for many editors. For example, the article has been tagged as a medical stub (in 2005) and as belonging to the following categories: Childbirth, Medical aspects of death, Signs of death, Forensic phenomenon, Obstetrics, and Pregnancy with abortive outcome.

Science and serendipity

According to Josh, one of the reasons he was motivated to contribute to the article was the way in which it was written:

> *There were words like—I can't remember now. But there were words like "brutal" and like—it was very ominous and dramatic sounding. It wasn't very factual. I mean, there was fact there, but it was hidden under a lot of dramatic language. Not encyclopedic language.*

Over the course of several months, he revised the article, adding sections and references, and responding to requests to make the content more accessible (less technical). One word, however, proved especially contentious. As Josh said, "one part that is corrected a lot—or used to be corrected a lot—was the word *serendipity*." For example, an unregistered IP address posted the following comment to the article talk page in 2012:

> The word serendipity is exclusively used for good things. To use it when discussing the death of a woman and her baby is utterly inappropriate, even if it is a quote from some sociopathic doctor. User 1 (talk) 18:03, 20 June 2012 (UTC)

Josh and I spent some time discussing this comment and the use of the word *serendipitous* in the article:

> *Some people will put that [criticisms of the word] in the corrections too. They'll delete that and write, "This isn't a serendipitous event." But, from the point of research, it definitely is. When you think of serendipity, you know, the word has very good connotations, but—regardless of connotations—the meaning is a beneficial event that happens by accident. In terms of research, it's all about timing. You can't really replicate this kind of research.*

The most recent research about post-mortem fetal extrusion include such "serendipitous" case studies as the death of a 34-year-old heroin addict in the eighth month of pregnancy (Schulz & Tsokos, 2005) and a 23-year-old pregnant woman killed in a car accident and resulting car fire (Pollak & Perdekamp, 2008), notable because the fetus was not expelled due to decomposition but rather trauma. Though the authors of these two studies do not use the word “serendipity” or refer to the events as such, they do benefit from these incidents. Writing about the moral implications of serendipity, Merton & Barber (2004) ask: “Do happy accidents (happy accidental discoveries) *really* happen? If they may be said to happen, *how* do they happen? Is it *right* that they happen? Or can their occurrence be justified?” (p. 157). Unlike Editor 1 who wrote “graphic/explicit definition, stay away if squeamish” in her edit summary, Josh, who has worked as a cemetery caretaker and on numerous archeological dig sites, offered no caveats about the article or concerns about the moral implications of serendipity in science. He was most concerned that the article was accurate and adhered to “encyclopedic language.”

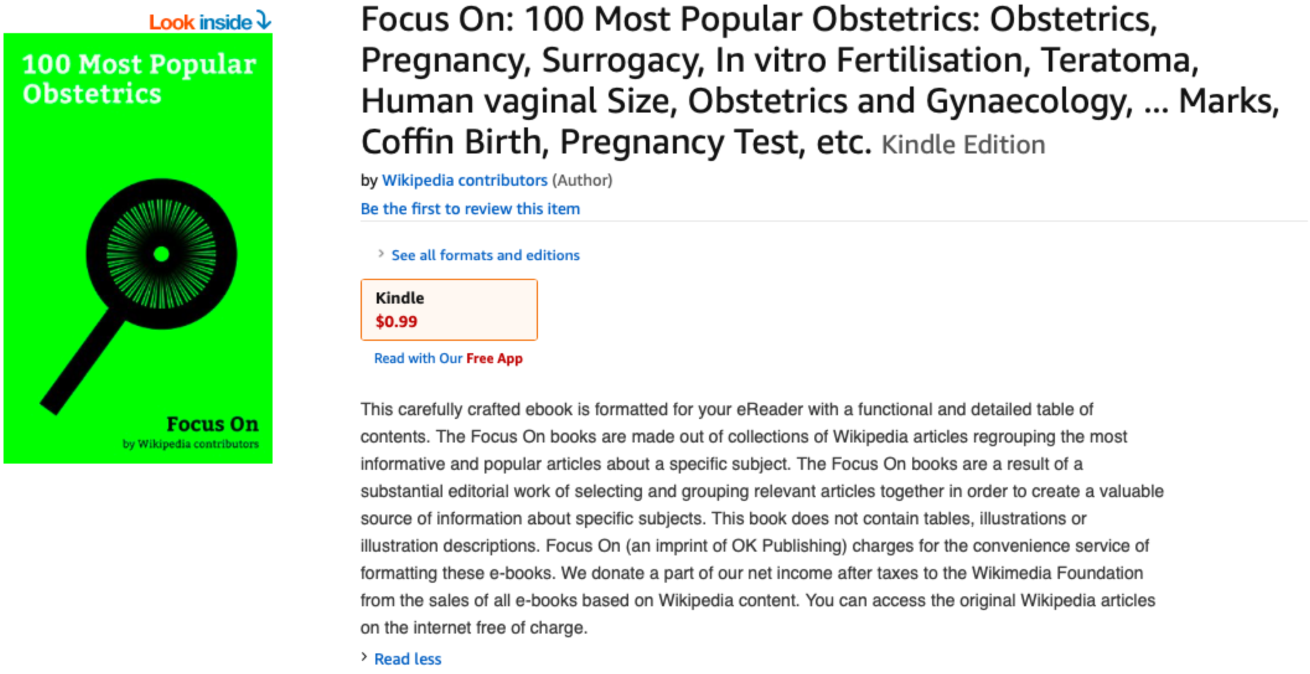
The commoditization of Coffin birth

One of the most interesting chapters in the life-history of *Coffin birth* centers around how its development into a Good article, its prominence in Internet search results, and its relationship with other types of media in the information ecosystem has contributed to its commodification. As noted in the Introduction section of this chapter, *Coffin birth* has been featured in Buzzfeed articles, but Josh talked about how it has also been featured on Facebook and referenced in television series:

> *Over the years, there have been spikes in viewers. I mean, I think when I first found it [the article], it was getting like a couple of hundred views a month, and now it averages like 8,000 to 11,000, and it spiked a few months ago with 60,000 views in one month. I know sometimes that happens because I’ll see those things on Facebook like “Ten most gruesome or scariest articles on Wikipedia,” and Coffin birth will be one of them. The day that that comes out, we see a spike in viewers. And the topic is mentioned once in a while in crime dramas. Like, I heard it mentioned in the TV show “Hannibal.” I heard the description [on TV], and I thought, “That sounds pretty familiar.” So, I had to look it up, and they changed it enough, but I think the TV show “Bones,” one time they paraphrased the Wikipedia article. But, in each case, the day after that episode airs, like, there will be a huge spike in viewers. Apparently, a lot of the general public—or the TV viewing public is occasionally checking on this article.*

Writing about the cultural biographies of things, Kopytoff argues that for something to be a commodity it must be produced materially of things and “culturally marked” as a commodity (1986). However, Kopytoff was writing before the Information Age and, perhaps, could not have anticipated how virtual commodities would be exchanged in an information ecosystem. Josh continued:

> *When I’ve done Google searches on Wikipedia, I’ve seen my article just everywhere, you know. I’ve even seen Amazon books where people just take Wikipedia articles and they just print them off as a PDF and bind them up and sell them on Amazon. “The Collected Works of Blah-Blah-Blah.” Some self-published project. And my article has been in one of these books. So, somebody is making money off of my work.*



Focus On: 100 Most Popular Obstetrics: Obstetrics, Pregnancy, Surrogacy, In vitro Fertilisation, Teratoma, Human vaginal Size, Obstetrics and Gynaecology, ... Marks, Coffin Birth, Pregnancy Test, etc. Kindle Edition

by Wikipedia contributors (Author)

This carefully crafted ebook is formatted for your eReader with a functional and detailed table of contents. The Focus On books are made out of collections of Wikipedia articles regrouping the most informative and popular articles about a specific subject. The Focus On books are a result of a substantial editorial work of selecting and grouping relevant articles together in order to create a valuable source of information about specific subjects. This book does not contain tables, illustrations or illustration descriptions. Focus On (an imprint of OK Publishing) charges for the convenience service of formatting these e-books. We donate a part of our net income after taxes to the Wikimedia Foundation from the sales of all e-books based on Wikipedia content. You can access the original Wikipedia articles on the internet free of charge.

Figure 1.7. A screenshot of an Amazon.com listing for an eBook comprised of 100 Wikipedia articles about "obstetrics," including the Coffin birth article. Note the description of the eBook which claims it is a "result of substantial editorial work of selecting and grouping relevant articles together."

What is curious about the series of "Focus On" books by "Wikipedia contributors" and similar series such as those reported on by Gawker's Max Read (2012) is that they reintroduce "editorial oversight" by hiring workers from the digital gig economy (De Stefano, 2015) to assemble content from the public domain:

> Molly, working from home or a Starbucks, would structure her books into chapters ("the way you'd outline an academic paper") by dragging the articles around a "sort of playlist page." Once finished, the "playlist" would be submitted to a Project Webster editor. Her pay was $5 per book […] plus another $1 for every book sold, decent enough for a part-time job you find on Craigslist — provided you work quickly enough. "My supervisor said experienced editors could average about five books an hour," she said. "I don't know how, because a book could take me anywhere from 20-90 minutes." (Read, 2012)

Although Josh intended for *Coffin birth* to be, in Kopytoff's words, a *gift*, it has become an unusual commodity in a complex information ecosystem. As Josh concluded, "So, yeah, capitalism. The commodification of somebody else's work." In this way, an object biography of *Coffin birth* "make[s] salient what might otherwise remain obscure" (Kopytoff, 1986) and provides an opportunity for future study of this particular phenomena surrounding the commodification of Wikipedia's content.

Coffin birth, 2019

Today, an Internet search for "coffin birth" results in Wikipedia's article topping the list. If the desire of every Wikipedia article is to rise to a position of prominence in the information ecosystem, then *Coffin* *birth* has succeeded. But is coffin birth relevant to women's health today? At first glance, I would say, "No." But by interrogating the *Coffin birth* article and learning about its life-history and, subsequently, the history of post-mortem fetal extrusion, *Coffin birth* like *Abortion-breast cancer hypothesis* serves as an interesting example of how different fields—from anthropology to medicine—and even the "modern public" have treated women's bodies as objects of fascination, horror, speculation, and study (e.g., Bashford, 1998; McNeil, 1998; Fournier, 2002; Chrisler, 2011a).

Discussion

What can the life-histories of these two seemingly "fringe" articles, *Abortion-breast cancer hypothesis* and *Coffin birth*, tell us about the reproduction of scientific knowledge related to women's health on Wikipedia? What does it mean that these articles have become Good articles and, thus, reached a point of stability? Below, I discuss how these object biographies raise questions about evidence and expertise as well as the reach of Wikipedia today. Finally, I review how the method of object biography adapted to study digital objects like Wikipedia articles offers us unique insights into both the topics under discussion and Wikipedia itself. I begin with a discussion about evidence.

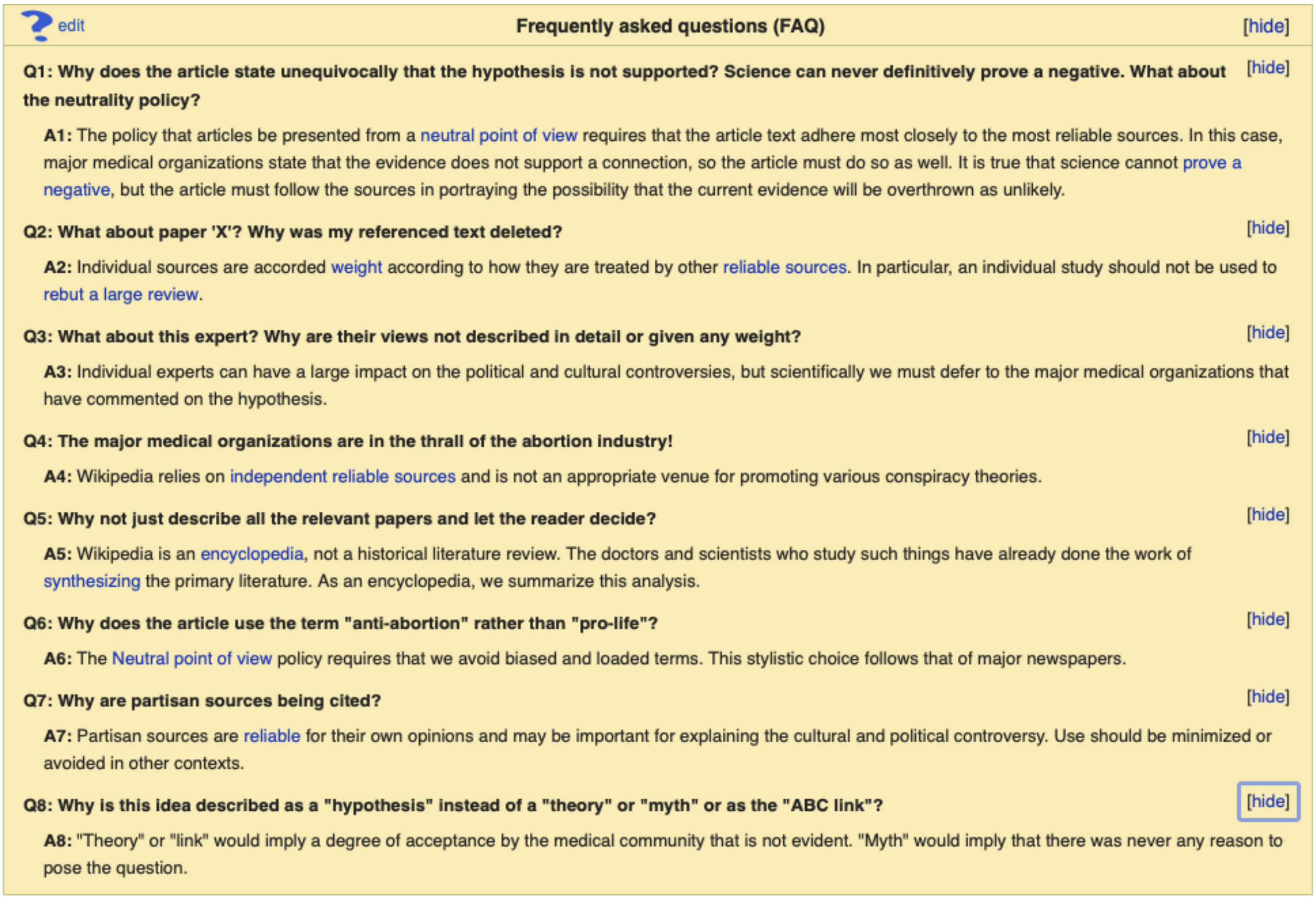
What counts as evidence?

In the life-histories of both of these articles we see moments in which there are questions about what counts as evidence in the reproduction of scientific knowledge on Wikipedia. Although Wikipedia's policies outline what should and should *not* count as evidence, as other researchers have noted, ambiguities in policy (Kriplean et al., 2007) and the problematic nature of consensus on Wikipedia (e.g., Forte & Bruckman, 2008; Reagle, 2010; Joyce, Pike & Butler, 2013) often leads to power plays between editors. In the case of the *Abortion-breast cancer hypothesis* article, Karsten's perseverance in editing the article and dedication to primary sources coupled with his Wikipedia expertise shaped the article for more than a decade—despite the efforts of other editors to convince him otherwise. He alone played a significant role in deciding the "facts" about the ABC link because he engaged in territorial behaviors (e.g., including the article on his watchlist, using notifications, dominating talk page discussions) and leveraged his role as an administrator to invoke policy and maintain specific sections. Over time, however, Editors B and C were able to sway Karsten to reconsider the evidence and rely on the decision made by the 2003 NCI workshop attendees rather than his own interpretation of the primary sources. But this was, in part, due to Karsten's disillusionment with Wikipedia ("kind of like how I'm done with Wikipedia") rather than Wikipedia's policies or editors' efforts to engage in collaborative knowledge reproduction.

In some cases, however, large groups of editors have made exceptions about what counts as evidence. Consider the *Chelsea Manning* article. In an unprecedented and controversial move, editors decided to change both the title of the article and the pronouns within in it to reflect Chelsea Manning's gender transition even though secondary and tertiary sources had yet to do so (Stern, 2013) Consider also articles about natural disasters or breaking news events that require a different approach to both knowledge reproduction and evidence (Keegan, Gergle & Contractor, 2013). So, it may be that what counts as evidence is dependent upon the topic under discussion. As Editor B noted on the *Abortion-breast cancer hypothesis* article talk page, scientific consensus takes time. What this means is that Wikipedia editors may need to revisit content related to scientific knowledge as an expert community's understanding of evidence shifts over time, as it has in the case of the ABC link. Article stability, however, may hinder editors from revisiting the evidence, particularly if an article has achieved Good or Featured article status.

The double-edge of article stability

Both *Abortion-breast cancer hypothesis* and *Coffin birth* have achieved Good article status and, with it, some degree of article stability. On the one hand, article stability ensures that editors who have worked on these two articles since 2004 do not need to revisit the same discussions. On the other hand, this means that new editors may be dissuaded from making changes to the articles and/or that editors may not revisit the same discussions in light of new evidence. One signal of stability is the Frequently Asked Questions (FAQ) template included on the article talk page for *Abortion-breast cancer hypothesis*. See Figure 2.7.



Frequently asked questions (FAQ)

Q1: Why does the article state unequivocally that the hypothesis is not supported? Science can never definitively prove a negative. What about the neutrality policy?

A1: The policy that articles be presented from a neutral point of view requires that the article text adhere most closely to the most reliable sources. In this case, major medical organizations state that the evidence does not support a connection, so the article must do so as well. It is true that science cannot prove a negative, but the article must follow the sources in portraying the possibility that the current evidence will be overthrown as unlikely.

Q2: What about paper 'X'? Why was my referenced text deleted?

A2: Individual sources are accorded weight according to how they are treated by other reliable sources. In particular, an individual study should not be used to rebut a large review.

Q3: What about this expert? Why are their views not described in detail or given any weight?

A3: Individual experts can have a large impact on the political and cultural controversies, but scientifically we must defer to the major medical organizations that have commented on the hypothesis.

Q4: The major medical organizations are in the thrall of the abortion industry!

A4: Wikipedia relies on independent reliable sources and is not an appropriate venue for promoting various conspiracy theories.

Q5: Why not just describe all the relevant papers and let the reader decide?

A5: Wikipedia is an encyclopedia, not a historical literature review. The doctors and scientists who study such things have already done the work of synthesizing the primary literature. As an encyclopedia, we summarize this analysis.

Q6: Why does the article use the term "anti-abortion" rather than "pro-life"?

A6: The Neutral point of view policy requires that we avoid biased and loaded terms. This stylistic choice follows that of major newspapers.

Q7: Why are partisan sources being cited?

A7: Partisan sources are reliable for their own opinions and may be important for explaining the cultural and political controversy. Use should be minimized or avoided in other contexts.

Q8: Why is this idea described as a "hypothesis" instead of a "theory" or "myth" or as the "ABC link"?

A8: "Theory" or "link" would imply a degree of acceptance by the medical community that is not evident. "Myth" would imply that there was never any reason to pose the question.

Figure 2.7. A screenshot of the FAQ box located on the talk page for the Abortion-breast cancer hypothesis article. This box was included in 2014 and debated by several editors, but it stands today (July 2019).

Editor B took issue with the establishment of this FAQ, arguing in a talk page comment that it was "a quasi-official imprimatur" of another editor's "violations of site policy." Indeed, the FAQ serves as an example of what René König (2013) describes as "immunization":

> *Immunization*: The article and its talk pages are immunized against contradictory interpretations by establishing an increasingly restrictive inclusion policy. This is supported by administrative actions, such as a (temporary) closure of the article to further edits. (p. 171)

This kind of "immunization" establishes a baseline of what editors have decided (or, in the case of the *Abortion-breast cancer hypothesis* article, one editor has decided) is and is not admissible evidence. The silver lining, here, is that (1) Good articles can be reassessed either by individuals or by the community as per the Good article reassessment (GAR) process[87]; (2) neither of the two article pages discussed above have been protected (i.e., closed to further edits), which is, perhaps, why Editor D was able to make the changes they did to *Abortion-breast cancer hypothesis* in 2017—despite the historical "Unsupported vs. rejected" debate and the FAQ box on the article talk page.

Whose expertise?

Both of these articles pose interesting questions about expertise. As discussed in Chapter 3, Wikipedia was never intended to be an encyclopedia written by experts; it was designed to be a content feeder for the expert-written encyclopedia Nupedia. Increasingly, though, as Wikipedia has aged and grown (Suh et al., 2009), specific topical areas of content creation and curation—including health and medical related content—have become saturated with experts who are recognized as such because they are professionals in their fields (see Chapters 2 and 5). What does this mean for "participatory expertise"? When I asked Karsten how he handled disagreements with domain experts including epidemiologists and oncologists, he said:

> *It's a toughie. Because then you could come back and say the dataset is small and incomplete. And then I'd exhale. And I'd say, "Whatever. You guys have more letters after your name than I do, so you're right and I'm wrong."*

As Carolyn and Eileen noted in Chapters 5 and 6, it *is* difficult to argue with professionalized expertise on Wikipedia, especially if the professionals with whom one is arguing are *also* expert Wikipedians. In fact, in response to concerns about the "fate of expertise" after Wikipedia, Larry Sanger, one of the co-founders of the site writes, "[I]f anything, Wikipedia's own policies actually reinforce the epistemic prerogatives of experts" (2009, p. 62). Similarly, writing about the creation of a German language Wikipedia article about the September 11, 2001 terrorist attacks on New York City, König finds that even "non-experts" on Wikipedia favor "expert" knowledge:

> Although laypeople apparently play a significant part in the text production, this does not mean that they favor lay knowledge. On the contrary, it is clearly elite knowledge of well-established authorities which is finally included in the article, whereas alternative interpretations are harshly excluded or at least marginalized. (König, 2013, p. 172)

However, the findings above suggest Wikipedia expertise (and dogged determination) can *temporarily* trump professionalized expertise and even suppress evidence from "well-established authorities (e.g., the 2003 NCI workshop), particularly if editors who are invested in the topic are administrators. To borrow Hara & Sanfilippo's (2016) phrase, administrators can become *judges* and, as evidenced in Karsten's

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[87] See https://en.wikipedia.org/wiki/Wikipedia:Good_article_reassessment

case, wield their localized power to determine not only what counts as evidence but also whose expertise matters most.

Masculinity and expertise

These two object biographies also surface interesting questions about the culture of Wikipedia and its relationship to a certain kind of masculinized expertise which I discuss in detail below.

Karsten was quick to describe himself as a geek. When I asked him how he spent his days, he told me about his job and about the websites he liked to visit. Finally, he said: "Let's see here. What else? And as hobbies, I work on computers. I'm an IT guy, so I repair and work on computers. I do the typical geek stuff." On the other hand, Josh was in the midst of finishing his dissertation when we talked, and he said he had time for little else. Although Karsten and Josh are both cisgender white men around the same age living in North America, my focus of analysis is not on their shared demographics. They have something else in common; they have both learned how to thrive in two spheres shaped by specific kinds of masculinized expertise: information technology (IT) and academia.

Since the late 1990s, there has been a growing body of work about IT and *geek masculinity* (e.g., Turkle, 1984; Kendall, 2000; Margolis & Fisher, 2003; Dunbar-Hester, 2008; Kendall, 2011; Ensmenger, 2012; Ensmenger, 2015; Hicks, 2017). In general, geek (or nerd) masculinity is depicted as rejecting hypermasculinized cultural norms such as physical strength and an interest in athletics in favor of intellectual pursuits (Ensmenger, 2012), prioritizing expertise and specialized knowledge (Massanari, 2017), professionalizing computer science and, thus, erecting barriers to prevent outsiders (usually women) from gaining access and authority all while claiming technocratic meritocracy (Hicks, 2017; Massanari, 2017 citing Turner, 2006), and de-emphasizing embodiment so that detachment is seen as a valuable and noble trait (Ensmenger, 2012; 2015).[88] Here, I am particularly interested in how geek masculinity fetishizes and grants authority to certain kinds of expertise. As Adrienne Massanari (2017) writes, "Geeks valorize expertise and specialized knowledge and geek culture often revolves around the acquisition, sharing, and distribution of this knowledge with others" (p. 332). Popular media depictions of geek masculinity—such as the television series "The Big Bang Theory" and "Silicon Valley"—normalize competitive knowledge-acquisition and mastery celebrated by displays of dominance. For example, in the Pup Culture's Detective video "The Complicity of Geek Masculinity on the Big Bang Theory," the narrator describes how the four main characters—all nerdy men—perpetuate "toxic masculinity" by policing one another:

> The relationship dynamics between Leonard, Sheldon, Howard, and Raj provides us with a microcosm of how this hierarchy of masculinities works. Practically every aspect of their friendship, from the personal to the professional, revolves around competition. In fact, they're lives are defined by a never-ending game of one-upmanship. ("Complicit geek," 2017)

When I asked Josh if there was anything else I should know about the *Coffin birth* article or women's health content on Wikipedia, he replied:

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[88] Wikipedia's policies (e.g., NPOV) and editors' resistance to including information about the emotional and psychological impacts of health conditions as discussed in Chapter 5 may also be related the culture's valorization of a certain kind of masculinized expertise that de-emphasizes embodiment and champions detachment. This is an opportunity for future work.

> *You know, there are a lot of guys out there who like to be really detailed and really technical about information. I mean, we see that earlier in our culture [Wikipedia's culture] with "Star Trek" or sci-fi fans in general, they can be really technically oriented and really detailed about their discussion, and I'm not sure why there aren't more women writing. I know in several discussions I saw that I didn't participate in, you know, a female editor had said something like, "Why are you guys always bothering me about sources? I just know this information." But that also struck me as a non-academic view, so that may have nothing to do with gender at all.*

Although Josh suggests that not referring to sources may have more to do with whether one has an academic or "non-academic view" rather than gender, he also associates being "really detailed" and "really technical about information" with the kind of men who participate in Wikipedia.

In contrast to geek masculinity, Michael Armato (2013) describes *academic masculinity* as a wolf in sheep's clothing; he argues that academic masculinity practices benevolent sexism while perpetuating hegemonic masculinity. Of a particular, poorly attended panel about academic masculinity, Armato writes:

> [W]e, as men, dominated a highly theoretical discussion, effectively silencing women in the room, who hardly participated. We cultivated a sense of distinction between ourselves, as academic men, and the world beyond the academic context; this was primarily accomplished by our allusion to the men "out there" who remain unnamed, but who I would argue were, in our consciousness, working class men and men of color. (p. 586)

Academia has been marked by a history of sexism and racism that merits more discussion than I can afford here (see Patton, 2004), but what is relevant to the discussion at hand is Armato's characterization of academic masculinity as men dominating "a highly theoretical discussion" while "effectively silencing women." This is the same kind of "never-ending game of one-upmanship" observed on "The Big Bang Theory" and in the conversations between Karsten, Editor B, and Editor C on the pages of the *Abortion-breast cancer hypothesis* article. Indeed, one of the major criticisms of academia—the "ivory tower"—is that it is far too often defined *only* by the mastery, demonstration, and defense of esoteric knowledge.

Yet, the culture of Wikipedia has much in common with the kind of masculinized expertise prominent in both IT and academia. Joseph Reagle (2013) argues the Free/Libre and Open Source Software movement (FLOSS or FOSS) in general and Wikipedia in particular exemplifies "the geek stereotype" and that the associated "discursive style can be unappealing." This discursive style—one dominated by masculinized expertise—gives way to what Bryce Peake (2015) describes as Wikipedia's "asshole consensus":

> The expertise of Wikipedians on all things Wikipedia, according to Wikipedians' actions, trumped any other form of expertise in knowledge production […] Thus, while a scientistic discourse underlies the logical system of Wikipedian policies, it is an actuarial and lawyeristic episteme structured by a history of encyclopediac male privilege […] that confers expertise on Wikipedians as gatekeepers of legitimate knowledge. […] Where the endless citations of policies constitute the erosive dimension of hegemony, the consensus process promotes and facilitates resignation to the hegemony of the asshole consensus.

As Peake notes and as I observed in my data, Wikipedia expertise can “effectively silence” any dissenting voices, and this kind of discursive move is often considered a “win” (display of power) in both IT (consider the “Dilbert” comic strip below; see Figure 3.7) and academia (e.g., Tannen, 2000; White & Lowenthal, 2011).

Figure 3.7. A panel from the “Dilbert” comic strip in which Dilbert, an engineer, “wins” by being “right.”

Finally, both geek masculinity and academic masculinity are implicitly *white* identities, and we know that the majority of editors who contribute to the English language Wikipedia are also white cisgender college-educated men.[89] In summary, given Karsten and Josh’s successes in their respective fields, their success on Wikipedia is not a coincidence.

The reach of Wikipedia

Finally, the commoditization of *Coffin birth* prompts us to ask important questions about the reach of Wikipedia. We know some Wikipedia articles feature prominently in Internet search results (McMahon, Johnson & Hecht, 2017) and that others inform the responses of virtual assistants like Siri and Alexa (Withers, 2018), but do we know how Wikipedia’s content infiltrates popular media sources like magazines, newspapers, television series, or movies? A recent advertising campaign by the North Face, an outdoor clothing and equipment supplier, that involved “hacking” images on Wikipedia so that the North Face logo featured prominently in a selection of images and, consequently, in Internet search results (Mervosh, 2019) underscored the reach of Wikipedia and the potential economic value of being included in its content. This is an area for future study.

The benefits of object biography

By considering the life-histories of *Abortion-breast cancer hypothesis* and *Coffin birth* we can attend to how these articles have grown and changed; something other researchers have done too. But we can also attend to how these articles serve as boundary objects between different communities (e.g., editors, readers, professionalized experts, laypeople) and how their lives continue outside of Wikipedia. The *Coffin birth* article provides an excellent case study for examining how a particular topic passes from

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[89] See https://meta.wikimedia.org/wiki/Community_Engagement_Insights/2018_Report and https://meta.wikimedia.org/wiki/Women_and_Wikimedia_Survey_2011

one domain of expertise to another (e.g., medical science to mortuary science to forensic anthropology) and how, perhaps due to its macabre appeal, a Wikipedia article lives on outside of the system in which it was created and, undercutting the nature of the commons, becomes a commodity repackaged in the digital gig economy and then sold by the world's largest online retailer. This is an area for future study too.

Limitations

This study has several limitations. For example, although I actively recruited other editors who had worked on *Coffin birth* and *Abortion-breast cancer hypothesis,* they did not reply, and so I did not speak to other editors about these two articles. Also, I did not speak to readers of these articles. Certainly, eliciting more perspectives directly from editors and readers would enrich this work. Second, this work is limited to the English language Wikipedia and limited to Wikipedia articles as digital objects. Whether the method and findings here are applicable to other UGC systems is unknown. Finally, admittedly, the topics of both of the articles discussed above are controversial or sensational to some degree and this has shaped their life-histories; though, after conducting five object biographies of diverse topics broadly related to women's health, I would argue controversy and sensationalism are inescapable when it comes to women's bodies. As McNeil (1998) writes, "The female body as both and object of knowledge and, as an object of danger (and hence male fear), haunts much of the history of science and medicine" (p. 61).

Conclusion

Writing about the history of the abortion-breast cancer debate, Jasen (2005) concludes:

> The inseparability of science from social context confronts all those who attempt to find their way through the maze of conflicting evidence, motives, aims and strategies that have characterized this debate, whether they are epidemiologists, historians, clinicians, or the women whose health is at the heart of the question.

We could say the same of Wikipedia. Given what we know about the site and its communities, are these two articles *really* outliers? Or are they representative of what Wikipedia has always been? Are they representative of how scientific knowledge about women's health has always been produced and reproduced? As one of my co-advisors has repeatedly observed, many social computing researchers today forget that, although the platforms they study may be new, the phenomena may not be. In the case of the production of scientific knowledge about women's health in the public sphere, men have always dominated the conversation; there have always been mazes "of conflicting evidence, motives, aims and strategies" that have shaped ideas about whose bodies matter and how they matter (see Chapter 2). Wikipedia affords a new kind of platform, one that allegedly democratizes knowledge production and, theoretically, affords an opportunity for *anyone* to participate in the reproduction of scientific knowledge. But, as discussed in Chapters 5 and 6, the obstacles to participating are non-trivial. And the findings in this chapter indicate the "laboratories" of Wikipedia—in which the "facts" themselves are decided—are no exception. One thing that is striking about both of the articles discussed above is that, apart from *Coffin birth* being created by a woman Wikipedian, women's voices are noticeably absent. This may be due to the topics under discussion, the participatory gender gap (there are fewer women on

Wikipedia in general), or the fact that there are fewer women administrators on Wikipedia.[90] But I would argue that the culture of Wikipedia and, in particular, its valorization and perpetuation of a very specific kind of masculinized expertise also plays a role in alienating potential editors of *all* genders and races who do not align with, value, and practice the same.

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[90] See https://meta.wikimedia.org/wiki/Women_and_Wikimedia_Survey_2011

Chapter 8: Summary and Conclusion

Summary

> They have a wonderful phrase in Wicca which to me recapitulates my argument today: it is that we learn to walk the twisted path. And a twisted path is not the one right true and only way, because there is no highway through life.
>
> Geoffrey C. Bowker, 2008

In Chapter 1, I asked, "What does one of the world's most powerful information sources—the encyclopedia 'anyone can edit'—have to say about women's health today? Given what we know about Wikipedia's participatory gaps, who is creating, curating, and controlling women's health information on the English language Wikipedia? Does it matter? What else might matter?" To answer these questions, I provide a brief overview of Chapters 5-7.

In Chapter 5, we learned that writing women's health content on Wikipedia is a complicated task, performed by relatively few editors compared to the larger editor population. We also learned that WikiProject Women's Health, the only project solely dedicated to creating, curating, and maintaining women's health information on Wikipedia, was established in 2015 by a handful of dedicated editors but is now, as one participant said, "dead in the water." Project members shared how they continuously negotiate the definition of women's health and struggle to find appropriate, high-quality, and representative images to illustrate women's health and anatomy articles. Project members also expressed a range of opinions about who can edit women's health content. At the same time, the banning of an editor who lacked a willingness to play by Wikipedia's rules and, according to a jury of her peers, the competence required to interpret medical content evidenced that, though the criteria for who can edit is not explicit, expectations are much higher than they would be for other content areas. Project members also expressed a range of perspectives regarding how they envision their audience for women's health information, which makes creating the content more ambiguous and challenging. Of interest to the series of questions above that I first asked in Chapter 1 is the finding that some women editors reported frustration with male editors (some of who are also medical practitioners) about including the emotional and psychological impacts of health conditions. However, as noted at the end of Chapter 5, an editor's beliefs about gender rather than an editor's gender identity *alone* may be a more salient factor to consider when thinking about the relationships between participatory gaps and content gaps.

In Chapter 6, we learned that health content on Wikipedia that disproportionately impacts women with intersecting identities may be more likely to be neglected in part due to factors beyond Wikipedia's control, like the stigmatization of female genitalia and health-related stigma. However, a careful consideration of three women's health articles previously neglected until I inadvertently drew editors' attention to them during interviews served to illustrate how Wikipedia itself—as a sociotechnical system—also contributes to the production and neglect of women's health content by perpetuating and magnifying existing biases in its policies and by directing editors' individual and collective attention away from neglected content with its tools. The question of including information about the emotional and psychological impacts of health conditions and discussing quality of life also emerged in this analysis. Finally, by interrogating the life-history of the *Women's health* article, we learned that one dedicated editor—in this case, a white, cisgender man who is a feminist and retired medical practitioner—can make a significant difference in how neglected content on Wikipedia is cared for, bringing *Women's health* to the status of a Good article, a status achieved by only 1 in every 199 articles on the English language Wikipedia.

Finally, in Chapter 7, we learned that the reproduction of scientific knowledge on Wikipedia is shaped by what Wikipedia counts as evidence, how editors interpret and ignore policies, and a culture of masculinized expertise. While these phenomena may not be new, by interrogating the lives of two seemingly fringe articles—*Abortion-breast cancer hypothesis* and *Coffin birth*—we learn that, even on Wikipedia, a site championed by some as an example of democratic knowledge production, professionalized and hegemonic expertise continues to dominate discussions. We also learned that editors can leverage their Wikipedia expertise to temporarily trump Wikipedia policies about evidence. For example, Karsten used his role as an administrator to shape both the *Abortion* and *Abortion breast-cancer hypothesis* articles according to his personal beliefs for more than a decade. Finally, we learned that, by adapting object biography to study Wikipedia articles, we can examine the ways in which certain articles function as boundary objects between different communities and domains of expertise as well as how they live on outside of Wikipedia. For example, the *Coffin birth* article—created by Josh as a gift—has not only been featured in Buzzfeed articles and television series but has also been repackaged in the digital gig economy and sold on the world's largest online retail site.

In summary, very few people—most of whom are Wikipedia experts and several of whom are medical professionals—are actively involved in creating, curating, maintaining, and reproducing women's health information on Wikipedia, though many more people (and bots) maintain what is built, repairing acts of vandalism and making small improvements. Does this matter? What else might matter?

To answer these two questions, I must first answer my final research question:

> *In what ways do participatory gaps (e.g., gender, age, race) on the English language Wikipedia shape women's health information on the site?*

Based on the empirical findings presented in Chapters 5-7, the (perhaps unsatisfactory) answer is: in numerous, insidious ways that are, at once, difficult to measure and may be misleading.

First, not having a diversity of voices informed by lived experiences and awareness of and knowledge about specific women's health conditions undoubtedly shapes how certain kinds of knowledge are produced and reproduced. Take, for example, Sara's account of how the "double whammy of stigma and emotions" impacts the inclusion (or exclusion) of information about controversial procedures like intact dilation extraction (IDX). Or consider that several women participants in my study repeatedly spoke about their struggles to convince male editors that information about the emotional and psychological impacts of health conditions should be included.

Second, if these kinds of voices are not present to critique or, in Hara & Sanfilippo's (2016) framing, serve as a *judge* to assess the kinds of information being included and excluded, then Wikipedia becomes a space in which hegemonic views of women's health—historically androcentric and reductive—grow and take hold. For evidence, consider the history of the *Women's health* article as presented in Chapter 6. For 11 years, it defined women's health as "health issues and matters specific to human female anatomy." Consider also that a white, cisgender man who is a former medical practitioner and a feminist was the editor who dedicated hundreds of hours to make *Women's health* a flagship article after 11 years of neglect.

So, does this mean we need to recruit more women to edit women's health information on Wikipedia? Do we need to recruit more women who are postmenopausal? Do we need to recruit more women of color? Maybe. I am not suggesting that enlisting more allies or "enlightened" or "woke" white, cisgender men *alone* will radically alter the creation, curation, and reproduction of women's health information on Wikipedia, but it may create a more hospitable culture (Peake, 2015). What I am suggesting is we first need to understand what produces these gaps (as noted in Chapters 3 and 5-7, race-related participatory gaps on Wikipedia, in particular, are currently understudied). We also need to broaden our consideration of participatory gaps to include editors' ideologies as salient factors too.

Implications

This dissertation work has implications for the broader discipline of information science as well as for several of its subdisciplines, including health informatics. It also has practical implications for Wikipedia. I begin with implications for Wikipedia, which are empirically-based and more narrowly defined.

Implications for Wikipedia

Lowering barriers to participation

If Wikipedia purports to be "the encyclopedia anyone can edit" and if the Foundation is dedicated to "knowledge as a service," then lowering barriers to participation is a crucial first step. Based on the findings and discussions in Chapters 5 and 6, I have two specific provocations: (1) improving the discoverability of WikiProjects, and (2) creating more opportunities for "lightweight" participation (Haythornthwaite, 2009).

First, WikiProjects offer the opportunity for new editors to become more involved in topical areas and/or tasks that interest them. But, right now, WikiProjects are challenging to discover. Today, when a new user signs up, they are greeted with a welcome message that redirects them to *Help:Getting started*, a Wikipedia page of 11,775 bytes that consists of a wall of texts and hyperlinks none of which mention WikiProjects.[91] As Kate and William, the former a new editor and the latter an experienced editor, noted in Chapter 5, they both stumbled across WikiProject Women's Health in the process of doing other things. They were not looking for the project because they did not know it existed.

Second, creating opportunities for "lightweight" participation would also lower barriers to participation by providing users with more explicit options for engaging without having to create an account or learn Wikipedia's policies and guidelines. Haythornthwaite (2009) defines *lightweight peer production* (LWPP) as "oriented to independent contribution" and "not primarily designed to create or maintain relationships among contributors." For example, WikiHow has introduced a top-level menu item "Help Us" illustrated by a small plant with two leaves. If a user clicks "Help Us," they see a dashboard containing multiple ways to become involved, some of which do no not involve creating an account or logging in (e.g., answering questions, reviewing tech feedback). Contrast this with Wikipedia's limited options: edit as an unregistered IP address or create an account and edit.

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[91] See https://en.wikipedia.org/wiki/Help:Getting_started

Relevant to women's health content on Wikipedia, making WikiProject Women's Health more discoverable has the potential to reinvigorate the project and broaden the contributor base while creating opportunities for lightweight participation has the potential to engage readers and draw editors' attention to neglected content. As suggested in Chapter 5, one can imagine a design intervention (similar to what Gilbert et al., 2013 suggest, but simplified and for readers rather than researchers) that allows readers of women's health articles to rate the accuracy, completeness, helpfulness, and/or readability of an article—perhaps even annotating specific passages—without clicking "Edit" or posting to an article talk page.

Building tools to identify and care for neglected content

Wikipedia has a host of tools dedicated to directing both individual and collective attention. Some of these tools provide instant gratification (e.g., vandal fighting) while other tools assume page views are the most critical metrics that should direct the community's focus. Although WikiProjects currently categorize articles by quality (e.g., stub, start, C-class, B-class) and importance (e.g., bottom, low, mid, high), the findings presented in the preceding chapters indicate there is a more significant design opportunity here. What if we could build a tool that channels feelings of ownership into feelings of stewardship and care? Recently there has been a trend in mobile apps in which users are motivated to engage, at least in part, because they feel responsible for *growing* something. In the case of Oak, a free meditation app launched by Digg founder Kevin Rose (Constine, 2017), as the user practices meditation, they grow "a little sapling […] into a mighty oak."[92] In the case of Forest, an app designed to help users be less dependent on their phones, users grow virtual forests they can then exchange for virtual currency to donate to the purchase of real trees for reforestation projects in five African countries (Livni, 2017). The editors I interviewed expressed pride in the articles they said they had "brought up to GA status," and it is common for editors to list these articles on their Wikipedia user pages. Since Wikipedia already uses *barnstars*, badges awarded by other editors to recognize good work[93], creating an opportunity for editors to opt-in to a feature that identifies and progressively rewards the care of neglected content is not outside of the norms of the community and would provide some instant gratification in a way that creating content does not.

Preventing editor burnout by providing social and emotional support

Providing support for unpaid labor is a contentious suggestion. I am not advocating for paid editing (though that is an interesting question deserving of study), but based on findings discussed in Chapter 5, I am advocating Wikipedia provide social and emotional support to prevent editor burnout. To someone outside of the community, this may seem like an obvious suggestion. But Wikipedia has a long history of squelching initiatives considered to be social in nature. Take, for example, Esperanza, a project founded in 2005 with the goal "to support the encyclopedia indirectly by encouraging a sense of community" by implementing a range of projects including alerting the project if an editor "was ill or feeling highly stressed due to issues on Wikipedia or in real life, or if someone left Wikipedia."[94] After a year, the project was nominated for deletion due to concerns of "cultish-ness," exclusivity, and potentially giving "new users the idea that Wikipedia is a place for socializing rather than working on an encyclopedia."[95] One month later, Esperanza was disbanded. But Wikipedia has seen a decline in editors

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[92] See https://apps.apple.com/us/app/oak-meditation-breathing/id1210209691

[93] See https://en.wikipedia.org/wiki/Wikipedia:Barnstars

[94] See https://en.wikipedia.org/wiki/Wikipedia:Esperanza

[95] See https://en.wikipedia.org/wiki/Wikipedia:Miscellany_for_deletion/Wikipedia:Esperanza/Archive1

since 2007 and, as evidenced in this dissertation work as well as in prior work by my colleagues and I (Menking, Erickson & Pratt, 2019), we know editors perform emotion work and seek support from one another off-Wiki (e.g., via Skype calls, private Facebook groups). Although lowering barriers to contribute by providing opportunities to engage in "lightweight" participation may relieve some stressors, administrators, power users, and editors who work on highly controversial or stigmatized content (e.g., women's health information) will continue to need social and emotional support. Denying this is dehumanizing and undercuts Wikipedia's claims to be a "community."

Implications for information science

Wikipedia matters

I am always surprised by how few people in the field of information science study Wikipedia. There is, of course, a core group of Wikipedia researchers. Many of these researchers approach the site with a quantitative lens and/or focus on it as an example of computer supported cooperative work and who are actively engaged in respective conferences and communities like the ACM International Conference on Supporting Group Work (GROUP), the ACM Conference on Computer-Supported Cooperative Work and Social Computing, and the International AAAI Conference on Web and Social Media (ICWSM). And then there are exceptional scholars like Noriko Hara and Sally Wyatt who interrogate Wikipedia from the perspective of social informatics or digital cultures, but who are not exclusively "Wikipedia researchers" (much to their credit) and who tend to either publish in journals or participate in conferences and communities like the Association for Information Science and Technology (ASIS&T) and Society for Social Studies of Science (4S) annual meetings. But Wikipedia is a rich and important site of study for a wide range of inquiry, and as Wikipedia's content becomes more and more integrated into other information systems and is used to train more and more algorithms, more information scientists should pay attention. Wikipedia *is* powerful, and it is only becoming more so. As Jemielniak & Aibar (2016) write, "For the good or for the bad, Wikipedia will stay and will most likely serve as the main source of knowledge—including scientific knowledge—for the generations to come" (p. 1776). I hope this dissertation prompts more information scientists, particularly those who do work in health informatics, to study Wikipedia.

Contributions

The contributions of this dissertation work are threefold. First, this dissertation work makes an empirical contribution to Wikipedia research and—by extension—to the CSCW and HCI literature about Wikipedia by being the first to explicitly consider women's health information on the English language Wikipedia and WikiProject Women's Health. Second, this dissertation work makes a methodological contribution to information science and its constituent communities by outlining how the method of object biography might be adapted to study a digital object. The method is particularly well-suited for critically interrogating the socio-cultural production of information. Finally, by interrogating assumptions about the relationships between participatory gaps and content gaps in UGC systems like Wikipedia and by providing empirical evidence that these relationships are more nuanced and complicated than prior work suggests, this dissertation also makes a unique contribution to future social computing research by providing another lens through which we might study these relationships.

Limitations

This dissertation work has several limitations. First, I have limited the scope of my engagement and study to the English language Wikipedia. As I describe in Chapter 3, Wikipedia now exists in more than 300 languages and although the English language Wikipedia is the oldest and largest, it is unique in many respects. Therefore, all of the findings here may not necessarily resonate with other language Wikipedias. Additionally, although I have interviewed editors who produce women's health content and I have interrogated women's health articles, I have not interviewed readers of women's health content or studied how Wikipedia's content about women's health is shared or integrated into other information systems. Furthermore, Chapters 5-7 are, in many ways, preliminary studies, and I address their specific limitations in the corresponding chapters. This is an inductive, qualitative piece of work; I make no claims about generalizability, but I anticipate I will pursue several of the ideas presented here in future work, moving toward substantive theory-building with more data and more time.

Perhaps the most disconcerting limitation of this dissertation work is that, despite my critique of framing women's health as limited to reproductive health, the majority of my object biographies (four of five) concern articles about sexual and reproductive health. This limitation is due, in part, to the uncontrollable nature of interview-based research; with the exception of William, Henry, John, and Simon, the editors who agreed to speak with me had not worked on the articles about non-reproductive health topics I selected for object biography candidates.

Future work

The limitations of this dissertation work provide fertile ground for future studies. I look forward to delving into many of the questions this work has raised, including but not limited to: If some content in a UGC system is more difficult to create (i.e., medical content), how might we design the system (e.g., user interfaces, tools, processes, policies) to reduce barriers to contributing? Who is the audience for Wikipedia's women's health information? Who decides who the audience is? How might embodiment and lived experiences motivate and impact the ways in which editors contribute to the site? How does Wikipedia's dependence upon Commons shape what can and cannot be illustrated in its articles? In what ways does the illustration of women's health content on Wikipedia perpetuate the medicalization of women's health? Is there room for patient expertise on Wikipedia?

I also look forward to pursuing some of the larger questions this dissertation work has raised, including interrogating the complicated relationships between participatory gaps and content gaps in UGC systems. What might we learn if we ask Wikipedia editors what they think about gender rather than what their gender is? Finally, I can also imagine a series of studies focused on how expertise is conceptualized and enacted across different UGC systems. Take, for example, WikiHow, a UGC system inspired by Wikipedia that uses a "green expert checkmark" within specific articles, including medical articles, to denote that an expert has contributed to or reviewed the content.[96] In what ways does this kind of explicit signal of professionalized expertise impact the editing and reading communities?

Finally, I hope this dissertation work provides fertile ground for other researchers as they proceed down their own twisted paths.

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[96] See https://www.wikihow.com/Special:ArticleReviewers#medical%20review%20board

Conclusion

> Imagine a world in which every single human being can freely share in the sum of all knowledge. That's our commitment.
>
> Wikimedia vision, n.d.

After more than five years of being an active-member researcher in the English language Wikipedia community, during which time I have participated in numerous ways (see Chapter 4), co-authored four studies about Wikipedia, and completed this dissertation work, I now find myself asking, "Should we abandon Wikipedia and start all over?" Many of the editors I spoke to—even the most fervent and productive—have asked themselves some version of this question at some point in time. As Karsten said, "you just end up disengaging from Wikipedia just to save yourself—yeah, save yourself the energy."

But, for some reason, I still believe in the promise of Wikipedia. It may be because I believe more in the promise of the people I have met along the way. I believe in Alex and his partner, who continue to welcome me into the movement even though I hesitate to call myself a Wikipedian. I believe in Sara, who is passionate about women's health and reproductive rights. I believe in Henry's tireless dedication to improving the quality of health-related information on Wikipedia. I believe in Eileen's determination to edit with older women in mind and Whitney's willingness to serve as a go-between for activists, advocates, and medical professionals. I believe in William's commitment to making *Women's health* a flagship article. I believe in these people and what they are trying to make of Wikipedia as it slouches towards its 20th birthday in 2021. In its first 18 years of life, it radically redefined what an encyclopedia could be in ways we could not have imagined. In its next decade of life, I can imagine a future in which it is no longer constrained by the genre of an encyclopedia, a future in which its technical infrastructure has been broken and bent and remade to prioritize care (of information and humans), a future in which its underlying epistemology has been rewritten to acknowledge different ways of knowing and different kinds of expertise, a future in which its community is diverse, inclusive, and welcoming, a future in which Wikipedia is more than a mirror of the world as it is. But then, it would be something else entirely.

Postface

This dissertation was not written for people who study Wikipedia. It was written for women like Diana Moss in Cape Town, who Googled *Intrahepatic cholestasis* at 2:00am because she was worried about her body and her pregnancy. It was written for women like Kate, the participant in my study who started editing Wikipedia because she was considering a breast reduction surgery and stumbled upon the *Breast hypertrophy* article. It was written, as another participant Eileen said, for all the grandmothers in the world who have just learned they have a cystocele or rectocele or a fistula and are terrified of what comes next. It was written for imaginary women like Sosi, who are sitting alone in a bathroom somewhere with the results of a pregnancy test in one hand and a mobile phone in the other. It was written for me.

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Appendices

Appendix A. Research about Wikipedia's participatory gender gap

Note: This table includes scholarly, peer-reviewed research focused explicitly on Wikipedia's participatory gender gap and published in English. It does not include research about content gaps assumed to be gendered, lightly reviewed work (e.g., dissertations, workshop papers) or popular sources (e.g., newspaper or magazine articles, blog posts), or scholarly, peer-reviewed research published in other languages. All work is listed in chronological order.

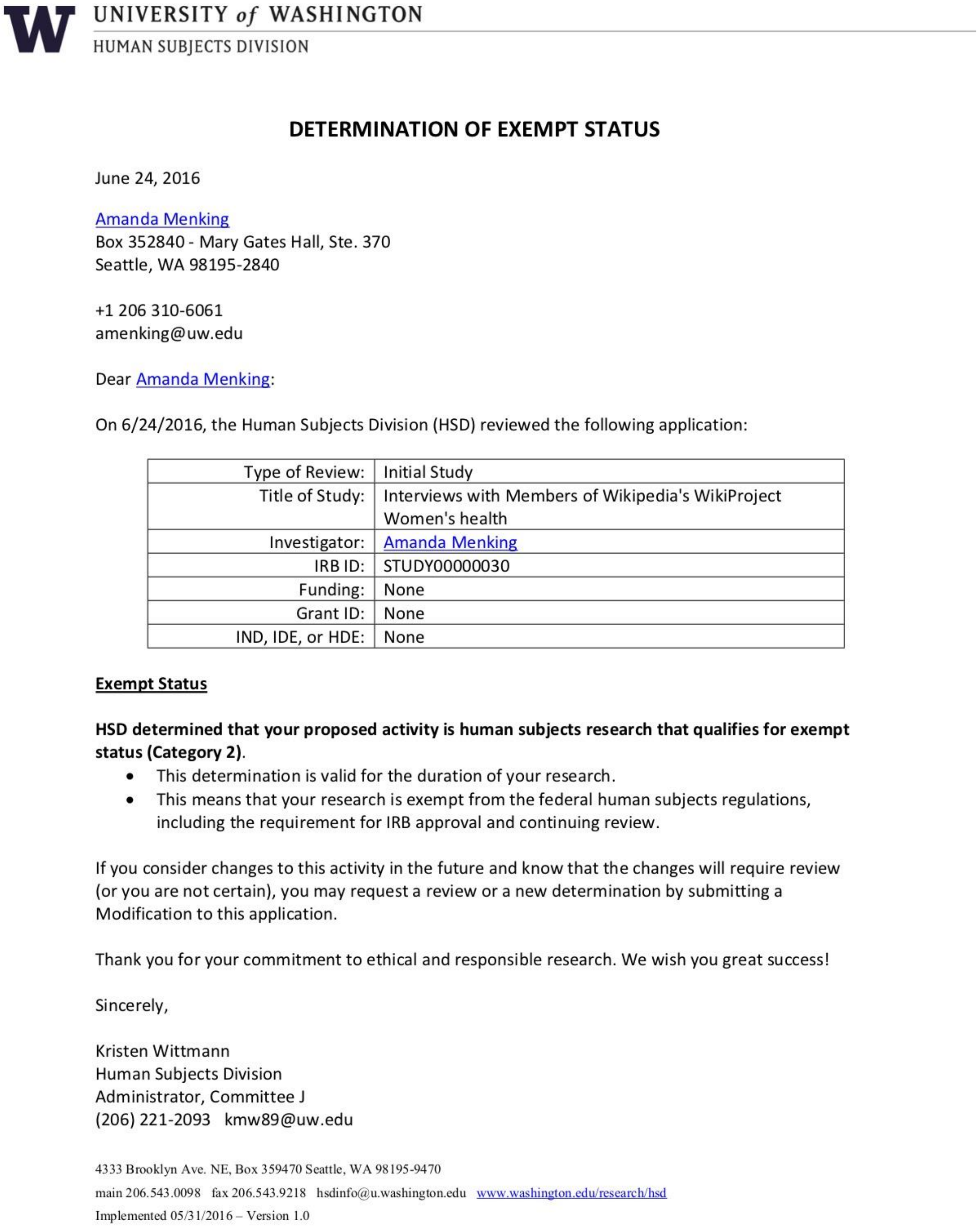
Citation	Study design	Characterization of participatory gender gap
Amichai–Hamburger et al., 2008	Online survey (*n*=139) including two psychological instruments (BFI and RealMe)	*Women who edit Wikipedia are more introverted than those who don't edit and may use the Internet to compensate.* "A significant difference in the level of extroversion was found between Wikipedia members and non-Wikipedia members, but only for women. This may be indicative of the fact that women seem to use the Internet as a compensative tool. Woman who are introverted and feel a need to express themselves and find this difficult in the offline world may be able to do so on the Internet."
Glott & Ghosh, 2010	Survey (*n*=176,192; *n*=43,912 English language)	*Wikipedia has a gender gap.* "Though both groups [readers and contributors] are dominated by men, there are significant differences in the gender composition of readers and contributors of Wikipedia. Contributors show a substantially larger share of males than readers. Among respondents only 12.64% of contributors are female."
Lam et al., 2011	Statistical analyses of Wikipedia data dump	*Women's edits are more likely to be reverted and women are more likely to be banned; topics of interest to women are not as well-developed. Wikipedia's culture may be problematic.* "Taken together, our results for RQ3: Gender-Conflict hint at a culture that may be resistant to female participation."
Antin et al., 2011	Statistical analyses of Wikipedia data, including data hand-coded (i.e., categorized) by Amazon Mechanical Turk workers	*The participatory gender gap is more nuanced than assumed and more evident among power users.* "[O]ur results confirm that, compared to men, there are far fewer women editing Wikipedia. Furthermore, there was a particular gender skew in revision quantity among the Wikipedians who do most of the work. Problematically, the most active Wikipedians are also those who largely set policies, arbitrate disputes, and do other high-level tasks into which biases of worldview and temperament can subtly creep. This is the very group among which women may need more representation, but also one which may be more difficult to break into."
Collier & Bear, 2012	Statistical analyses of a sub-set of UNU-MERIT survey data	*Women do not like conflict and/or criticism, and they lack confidence. Wikipedia is not designed to foster a supportive, pro-social environment, which women require.* "This study found strong support for the hypothesis that the gender contribution gap is due in part to responses to conflict. While Wikipedia is the encyclopedia that anyone can edit, the process of doing so is not without interpersonal difficulty. […] Women on average tend to prefer collaboration to competition and criticism. In Facebook and Twitter and other more social platforms we find women are heavily involved. However, Wikipedia and other knowledge repositories by their culture and policies proclaim to be a place that is not meant to be social."

Citation	Study design	Characterization of participatory gender gap
Laniado et al., 2012	Statistical analyses of Wikipedia data, including Crowdflower hand-coding of gender and sentiment analysis (ANEW) of talk page threads	*Women and men communicate differently on Wikipedia, with women engaging in more positive emotions, writing longer messages, and citing Wikipedia policies more often. The latter characterization prompts questions regarding how women lead in masculine environments.* "Female editors tend to work in topics in which the discussion has a more positive tone. They also receive more positive comments on their user talk pages. Both can be interpreted as signals of positive emotions brought by women, although we have also seen that sometimes messages addressed to them have a paternalistic tone that may not be constructive. Our results raise interesting questions on the role of women with respect to power in a prevalently masculine community. […] active female editors express themselves similarly to male administrators irrespectively of their own administrator status, and female administrators and non-administrators behave similarly; they also tend to cite more often Wikipedia policies, a trait shared by experienced editors and administrators."
Hill & Shaw, 2013	Propensity score adjustment comparing a sub-set of UNU-MERIT survey data with data on Wikipedia readership from the Pew Research Center's Internet & American Life Project	*Wikipedia has a gender gap in participation, though it's slightly smaller than the UNU-MERIT study reported. Also, women are less likely to participate in surveys.* "We estimate that the proportion of female US adult editors was 27.5% higher than the original study reported (22.7%, versus 17.8%), and that the total proportion of female editors was 26.8% higher (16.1%, versus 12.7%)."
Eckert & Steiner, 2013	Interviews (*n*=53; *n*=20 Wikipedia contributors; *n*=33 Wikipedia non-contributors)	*Wikipedia's culture is problematic.* "Wikipedia's geek heritage has worked against enhancing its inclusivity. […] Women's inclusion in Wikipedia is crucial to promoting its democratic potential…"
Morgan et al., 2013	Design, deployment, and preliminary analysis (via editor activity and survey; *n*=196 Teahouse guests and *n*=71 Wikipedians) of The Teahouse	*Wikipedia's culture and norms are challenging for newcomers, and even when Wikipedia provides women newcomers with a welcoming space, the gender imbalance impacts their experiences.* "We have shown that both new editors and Wikipedians find the space itself and the activities it supports to be engaging and worthwhile, and provided evidence that Teahouse offers opportunities for positive socialization, social interaction, and interactive editor support that other support spaces and tried-and-true socialization strategies do not. […] Furthermore, as most Teahouse hosts who were active in the Q&A forum are male, we believe that there may be further gender dynamics to be explored in terms of the host/guest interaction."
Reagle, 2013	Naturalistic inquiry based on six years of participant observation and 200+ documents	*Geek culture (e.g., identity and behaviors), anonymity, and the anarchic–libertarian ethic of open source communities like Wikipedia contribute to the gender gap.* "I argue that some otherwise commendable features of the free culture movement also contribute to the gender gap. That is, the geek stereotype and discursive style can be unappealing, open communities are especially susceptible to difficult people, and the ideas of freedom and openness can be used to dismiss concerns and rationalize the gender gap as a matter of preference and choice."
Hargittai & Shaw, 2015	Quantitative analyses of longitudinal survey data of college students (*n*=547)	*Women either have lower Internet skills or lower confidence in their skills and are, thus, less likely to contribute.*

Citation	Study design	Characterization of participatory gender gap
		"Our findings suggest that Internet skills are an extraordinarily robust predictor of contributing to Wikipedia and also help explain a key dimension of the gender gap among Wikipedia editors."
Menking & Erickson, 2015	Interviews (*n*=20) with women Wikipedians	*Wikipedia's culture, including policies and norms, require women to engage in taxing emotional work.* "Some of the participants interviewed for this study may be acting as proverbial canaries in the coal mine, their emotional work signaling a potentially toxic environment within Wikipedia. If women who adhere to the norms and share the underlying mission and epistemology of Wikipedia must engage in emotional work to participate as editors, administrators, and WMF employees, then what does it cost other individuals to conform to the Wiki way?"
Gruwell, 2015	Interviews (*n*=3) with women Wikipedians and textual analysis of Wikipedia's policies	*Wikipedia's epistemological and rhetorical stance privileges "objective" knowledge, and its policies exclude feminist ways of knowing.* "[…] Wikipedia functions as a rhetorical discourse community whose conventions exclude and silence feminist ways of knowing and writing."
Peake, 2015	Autoethnography (writing articles about sexual violence that were then deleted)	*Wikipedia's culture (e.g., policies and practices) enables and perpetuates an "asshole consensus" that rejects any information that threatens male privilege.* "On Wikipedia, a misogynist infopolitics dictates that 'factual information' is information pertaining to, but not threatening of, a sense of masculinity that is situated in a social world that extends beyond the confines of Wikipedia. This sense of masculinity, and its concomitant misogyny, can be enacted and protected by both men and women […]. Thus, rather than 'ontologize' gender in criticizing Wikipedia's gendered hostilities, or focus on the positivistic 'how many women equals equality' question that defines Wikipedia's 'Gender Gap' civilizing mission, my focus in this article is on how misogynist infopolitics define Wikipedians' interactive habits, shaping the social environment in ways that make Wikipedians of many genders and sexualities hostile to information that challenges forms of male privilege understood to be diminishing or endangered by institutional diversity initiatives."
Bear & Collier, 2016	Statistical analyses of a sub-set of UNU-MERIT survey data	*Women do not like conflict and/or criticism, and they lack confidence. Women who responded to the survey did not lack discretionary time as predicted.* "Significant gender differences were found in confidence in expertise, discomfort with editing, and response to critical feedback. Women reported less confidence in their expertise, expressed greater discomfort with editing (which typically involves conflict) and reported more negative responses to critical feedback compared to men. […] Also contrary to our prediction, there was no gender difference in discretionary time, and thus limited time did not explain the gender gap in contribution to Wikipedia among our sample of occasional contributors."
Protonotarios, Sarimpei & Otterbacher, 2016	Survey of Greek Wikipedia editors (*n*=61) and readers (*n*=344)	*Women lack confidence, but they do not have less discretionary time than men. Women tend to edit for different reasons, including personal satisfaction and enjoyment.* "The results of our readership and editor surveys at Greek Wikipedia confirmed that some previous findings resulting from research on all of

Citation	Study design	Characterization of participatory gender gap
		Wikipedia also apply specifically to the Greek language community. […] Taking the results of our readership and editor studies together, it appears that women more often read and/or edit Wikipedia for their own personal satisfaction and enjoyment.”
Ford & Wajcman, 2017	Analysis of Wikipedia’s infrastructure (i.e., logics, software, policies)	*The Wikipedian identity valorizes geek masculinity.* “The infrastructure lens we have adopted here shines a light on the less visible sources of gender inequality. It reveals how the very identity of a Wikipedian, its habitus, still reflects the history of technoscience as an almost exclusively male province. Unless Wikipedia radically changes its own culture of knowledge production, women will remain on the edges; our knowledge will once again be marginalized.”
Shane-Simpson & Gillespie-Lynch, 2017	Editing experiment with college students (*n*=200) and quantitative analysis of follow-up survey	*Women added more content, especially when feedback was constructive. Women tended to perceive anonymous editors as men.* “[…] gender differences in collaborative editing behaviors appear to be influenced by both the composition of mixed-gender collaborative groups and the communicative norms that these groups use.”
Shaw & Hargittai, 2018	Survey data (*n*=1,512) and development of a model	*Gender is a less relevant factor early in the “pipeline” of participation.* “The results provide empirical support for the idea that knowledge gaps contribute to a pipeline of online participation in the networked public sphere. […] Education, Internet skills, and age have robust associations with outcomes at every step in the pipeline. Other factors, such as income, employment status, and racial/ethnic background, help explain earlier stages in the pipeline even though they do not associate with who contributes content. Gender only matters at later stages in the pipeline, despite the important and valid emphasis of prior research and public debate on the Wikipedia gender gap.”
Menking, Erickson & Pratt, 2019	Interviews (*n*=25) with experienced women Wikipedians	*Wikipedia consists of many different online and offline spaces with different characteristics and porous boundaries; some are more or less safe. Experienced women editors have learned how to navigate these spaces even when they feel unsafe.* “Our analysis shows Wikipedia functions as both a multidimensional and porous space encompassing a spectrum of safety. Navigating this space requires these women to employ sophisticated tactics related to identity management, boundary management, and emotion work.”

Appendix B. Determination letter from University of Washington HSD



UNIVERSITY of WASHINGTON
HUMAN SUBJECTS DIVISION

DETERMINATION OF EXEMPT STATUS

June 24, 2016

Amanda Menking
Box 352840 - Mary Gates Hall, Ste. 370
Seattle, WA 98195-2840

+1 206 310-6061
amenking@uw.edu

Dear Amanda Menking:

On 6/24/2016, the Human Subjects Division (HSD) reviewed the following application:

Type of Review:	Initial Study
Title of Study:	Interviews with Members of Wikipedia's WikiProject Women's health
Investigator:	Amanda Menking
IRB ID:	STUDY00000030
Funding:	None
Grant ID:	None
IND, IDE, or HDE:	None

Exempt Status

HSD determined that your proposed activity is human subjects research that qualifies for exempt status (Category 2).

- This determination is valid for the duration of your research.
- This means that your research is exempt from the federal human subjects regulations, including the requirement for IRB approval and continuing review.

If you consider changes to this activity in the future and know that the changes will require review (or you are not certain), you may request a review or a new determination by submitting a Modification to this application.

Thank you for your commitment to ethical and responsible research. We wish you great success!

Sincerely,

Kristen Wittmann
Human Subjects Division
Administrator, Committee J
(206) 221-2093 kmw89@uw.edu

4333 Brooklyn Ave. NE, Box 359470 Seattle, WA 98195-9470
main 206.543.0098 fax 206.543.9218 hsdinfo@u.washington.edu www.washington.edu/research/hsd
Implemented 05/31/2016 – Version 1.0

Appendix C. Recruitment messages sent via Wikipedia email

Message to recruit explicit members of WikiProject Women's Health

I'm a PhD candidate at the University of Washington Information School, and I've been working on research related to women and Wikipedia for the past ~2 years. [1]

For my dissertation, I'm considering women's health and Wikipedia. As Phase 1 of my project, I'd love to interview the explicit members (e.g., those listed on the project page) of WP: Women's health.

Would you be willing to participate? If so, I can send you more information, a consent form, etc.

Thanks for the work you do!
Mssemantics / Amanda

[1] https://meta.wikimedia.org/wiki/Grants:IEG/Women_and_Wikipedia/Final

Message to recruit editors of women's health articles

I'm a PhD candidate at the University of Washington Information School, and I've been working on research related to women and Wikipedia for the past ~2 years. [1]

For my dissertation, I'm considering women's health and Wikipedia. As Phase 1 of my project, I'd love to interview people who contribute to articles about women's health.

Would you be willing to participate? If so, I can send you more information, a consent form, etc.

Thanks for the work you do!
Mssemantics / Amanda

[1] https://meta.wikimedia.org/wiki/Grants:IEG/Women_and_Wikipedia/Final

Message to recruit editors who contributed significantly to candidates for object biographies

I'm a PhD student at the University of Washington in Seattle, WA. As a part of my dissertation work, I'm collecting data about 12 articles related to Women's Health. One of the articles I'm analyzing is [title of article]. As you have contributed significantly to this article, would you consent to an interview?

We can chat via Skype, Google Hangouts, or phone (or your choice). You would receive compensation in the form of an Amazon gift certificate for $25.00 USD. I'm also happy to send you more information about the study and the interview if you'd like.

Best,
Amanda Menking / Mssemantics

Appendix D. Sample consent form

Researcher: Amanda Menking, University of Washington Information School
Title of Research Study: Interviews with Members of WikiProject Women's Health

About the Study

The purpose of this study is to understand better the purpose and goals of WikiProject Women's Health by conducting interviews with both explicit (e.g., listed on the project page) and implicit (e.g., users with registered accounts who have made more than 10 edits to articles associated with WikiProject Women's Health) members.

Research Details

If you consent, you will be asked to participate in a 60-90-minute interview with me, the researcher. Interviews may take place online via Skype, Google Hangout, email, telephone, or in person. Pending your consent, Skype, telephone, Google Hangout, and face-to-face interviews will be audio recorded. In these interviews, you will be asked about your experiences with Wikipedia and your participation in WikiProject Women's Health.

You do not have to respond to any questions you do not feel comfortable answering, and you may give as little or as much information as you choose. You may withdraw from the study at any time. If you choose to withdraw from the study after the interview is completed, please email me at amenking@uw.edu. You will incur no negative consequences, and I will not use any of your information in my study.

The results of this study — including direct quotations from interviews — may appear in published form in conference presentations or in articles written for academic journals. They may also appear in my doctoral dissertation. In addition, I may share the results of my work with the Wikipedia community via a submission to *The Signpost* or via the WMF blog.

Your participation in this study is voluntary. You are free to decide if you would like to participate or not, and you may withdraw from the study at any point during the study before publication of the findings.

Confidentiality

Your privacy will be protected to the maximum extent allowable by law. Your name (either your real name or your Wikipedia username) will not appear in conjunction with the data gathered during this interview— unless you expressly give me permission to use your name.

Your responses are completely confidential, and I do not monitor IP addresses. No third party will have access to your responses.

Although every effort will be done to ensure confidentiality of your responses, you should be aware that all Internet-based communication is subject to the remote likelihood of tampering from an outside source. IP addresses are not recorded, and data will be removed from the server.

Time Obligation and Compensation
Participation in this interview will take approximately 60-90 minutes of your time. You will not receive any form of monetary compensation for this study. However, if you have any ideas about how I might give back to the WikiProject to honor your time and work, please let me know.

Questions or Concerns
Your decision to participate in this study is not required. Although the University of Washington's Institutional Review Board (IRB) has approved this project as exempt, you may contact them with any question, comments, or concerns — anonymously, if you wish.

You may use the following citation to ask questions about my IRB: **HSD STUDY00000030**.

University of Washington Institutional Review Board (IRB) and Human Subjects Division (HSD)
(206) 543-0098 telephone
(206) 543-9218 fax
hsdinfo@uw.edu

Consent
By signing "yes" I am agreeing to voluntarily enter this study. I understand that, by signing this document, I do not waive any of my legal rights. I have had a chance to read this consent form, and it was explained to me in a language that I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I will not receive any form of compensation for participating in this study.

I also understand that if I submit this consent form via email, the process of typing my name below and completing the interview indicates my voluntary agreement to participate. My signature below also indicates that I am 18 or older.

Yes, I agree to participate in this study.

______________________________ ____________________
Signature Date

____
Printed name

Appendix E. Sample interview protocol

Background questions

How do you spend your days?
Tell me a little about your experiences as a Wikipedian.
Which WikiProjects do you belong to?
How long have you been participating in WikiProjects?
In which WikiProjects are you most active?

Participation questions

What was your involvement in the creation of WikiProject Women's Health?
Why did you decide to participate in this specific WikiProject?
What do you hope to accomplish by participating in WikiProject Women's Health?
What has been your greatest contribution to WikiProject Women's Health?
What would prevent you from contributing in the future?

Information questions

Why do you think there needs to be a specific WikiProject devoted to women's health given there's already a WikiProject devoted to medicine and one devoted to reproduction and sexual health?
What kinds of information about women's health are missing from Wikipedia?
What kinds of information about women's health are most often deleted from Wikipedia? Any AfDs I should review?
What are the most important articles about women's health that need to be written?
How do you decide what to include/exclude when you write an article?
Is there anything else I should know?