

# Reimagining (Women's) Health: HCI, Gender and Essentialised Embodiment

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An ever-increasing body of work within HCI investigates questions of around “Women’s Health” with the aim to disrupt the status quo of defaulting to an implicit norm of cis-male bodies. This laudable and feminist project has the potential to drastically improve the inclusivity and availability of health care. To explore how this research attends to gender, embodiment and identity, we conducted a critical discourse analysis of 17 publications explicitly positioning themselves as works concerned with “Women’s Health”. We find essentialised articulations of embodiment and gender, though little discussion on the intersections of race, class, sexuality and cultural contexts. Through two speculative designs, we illustrate potential responses to our analysis: The Shadow Zine, a reflection of self and the Compass, a token for community care.<sup>1</sup> Our work provides an opportunity to develop a broader frame of gender and health, one that centers (*gendered*) *marginalised health* by attending to the power structures of existing medical practices and norms.

CCS Concepts: • **Human-centered computing** → **HCI theory, concepts and models**; • **Social and professional topics** → **Gender**; *Race and ethnicity*; *Religious orientation*; *People with disabilities*; *Geographic characteristics*; *Cultural characteristics*; • **Applied computing** → *Consumer health*;

Additional Key Words and Phrases: Gender, essentialism, embodiment, health, critical theory, speculative design, marginalisation, women’s health

## ACM Reference format:

Os Keyes, Burren Peil, Rua M. Williams, and Katta Spiel. 2020. Reimagining (Women’s) Health: HCI, Gender and Essentialised Embodiment. *ACM Trans. Comput.-Hum. Interact.* 27, 4, Article 25 (August 2020), 42 pages. <https://doi.org/10.1145/3404218>

<sup>1</sup>Caution: The article touches on several potentially triggering topics such as sexism, racism, colonialism, ableism and domestic violence.

Part of this work received financial support by Microsoft in the form of an Ada Lovelace Fellowship as well as by the Austrian Science Fund in the form of a Hertha Firnberg Scholarship (T 1146-G).

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1073-0516/2020/08-ART25 \$15.00

<https://doi.org/10.1145/3404218>

## 1 INTRODUCTION

With the recent somatic turn in Human–Computer Interaction (HCI) [122], human bodies have implicitly and explicitly stepped further into the foreground of our inquiries. One area in which this is particularly prominent is work that deliberately locates itself within “Women’s health”, work which this special edition (and this article) centrally address. Research in this area seeks to advocate for and participate in a resistance to the frequent practice of treating the cis, male body as the (unmarked) norm [33] in medicine and health contexts [10]. It is frequently positioned as critical, feminist and liberatory, and both this framing and the work itself constitutes a source of hope and optimism for many who feel invisible in the default conceptions of health-related research generally and within HCI.

But as Rode reminds us, feminist practice requires not just applied intervention, but reflexive inquiry that attends to the way in which practitioners’ work shapes and is shaped by gender’s material and discursive attributes [150]. While feminist practice offers the potential for liberation, a feminist practice that does not seek to reflect on its own assumptions and inheritances risks leaving justice only partially done. If we do not examine and critically reflect upon our own notions of “health” and “women”, we risk reinforcing rigid and essentialised understandings of those terms. Accordingly, this paper seeks to inquire into the ideas of gender and health at use in HCI work that identifies itself as focused on “Women’s Health”, for the purpose of increasing the liberatory potential of that work.

Taking this special edition framing of “reimagining women’s health” as inspiration, we analyse the current conceptions of both “womanhood” and “health” deployed in prior research in the area, and then speculatively design HCI interventions that use different conceptions—conceptions that increase the range of people such work might benefit, and the range of concerns that might be addressed. Conducting a literature review of existing HCI work explicitly deploying a notion of women’s health, we sought to understand how this research discursively frames users’ embodiment and its relation to gender, and what assumptions and silences appear in relation to other intersecting axes of medical exclusion. Demonstrating how current work succeeds at questioning existing norms, we *also* demonstrate ways in which the framings of gender and health in use artificially limit its scope and potential, and the possible ways we might imagine our relationships with technology.<sup>2</sup> While existing work successfully and importantly troubles the *status quo*, we demonstrate that it has a tendency to assume a binary, embodied and hetero-cis-normative model of gender, which unintentionally leads to work reproducing many of the same forms of exclusion, marginalisation and violence at the heart of the systems it is fighting against.

Out of a desire to trouble *these* norms in turn—a desire that stems from our appreciation of both the importance and additional potential of work in this area, and our agreement with Bardzell as to the feminist potential of *critical* and *generative* engagements with design [22]—, we provide not only this analysis, but a range of recommendations for future work around (gendered) marginalised health, and a set of speculative designs in which we both suggest directions forward and sympathetically reflect on the ultimate impossibility of a single feminism for all—and the solidaric *possibilities* of pursuing relations and sharing between different feminist projects regardless.

## 2 THE WOMEN’S HEALTH MOVEMENT(S)

### 2.1 A Perspective on the Women’s Health Movement

Gender, health and oppression are fundamentally intertwined; as Doyal puts it, “women have always been involved in struggles about health - often in ways that have gone unrecognised and entirely unrecorded” [54]. In popular (western) narratives, “women’s health” as a term of art and

<sup>2</sup>We thank Reviewer 1 for providing us with this excellent phrase describing the motivation for our work.

movement arose in a specific historical context: that of 1970s second-wave feminism in the United States. The work of the women's health movement involved several strands. The most visible and traditional consisted of interventions within legislative and policy arenas. Within the United Kingdom, for example, the movement organised to prevent attempts to push back the legalisation of abortion in 1967; and within the United States, they worked to *enable* the legalisation of abortion [138]. Efforts were made to reform drug testing processes, which largely focused on middle-aged white men (with predictable results when medication was made available to the general population) [62], and better include women's voices within health-care decision-making as both patients and providers [54]. Work was undertaken to challenge the way gender flowed into diagnostic approaches and patient legibility, primarily through the discounting of women's pain or conditions [135].

While these were the most visible feminist interventions in the "public sphere", they were a distinct minority of the movement's work. Faced with a paternalistic medical structure, other efforts moved past attempts to reform and sought to establish a new system of medicine under the control and direction of the women subject to it. Women's self-help health groups, beginning with one in 1970, quickly spread to number over 1,200 within 3 years. In the United States, self-published and communally-published books, most prominently *Our Bodies, Ourselves*, made medical knowledge and self-examination more widely available [90]. Feminist collectives organised access to abortion and counselling in times and places where it was illegal [24].

This work has been vital to the lives of millions, and inspiring for successive circles of activists—but only represents part of a complex history. There are myriad examples of women in non-Western contexts, often surviving the day-to-day realities (or consequences) of Western colonialism, working on questions of health. One could point to the work of activists such as Malak Hifni Nassef, advocating for maternal health services in Egypt [18], where Aida Al-Dawla notes campaigns against female genital mutilation by the 1920s [7]. Sonja Kim, discussing birth control in colonial Korea between 1910 and 1945, highlights the presence of feminist organisations arguing for access for reasons of freedom, autonomy and liberation, despite an overwhelmingly Malthusian discursive context [111]. Examinations of *Our Bodies, Ourselves*, written by a (white, middle class) organisation in Boston, rarely mention the black feminist Combahee River Collective active at the same time and place—while discussion of the Collective rarely mentions its members' work on questions of health [137]. These events and histories (and many like them) are rarely surfaced in histories of "women's health", which often centre and idealise Western history, culture and (highly charged) notions of "modernity" and "civilisation". As a consequence, they leave movements vulnerable to what Khader calls "missionary feminism"; the treatment of feminism as a one-size-fits-all model in which the solution to any problem can be found in western (white) feminists' ideas and visions of justice [110]. This narrow view, and consequential erasure of variation (or more accurately, implicit treatment of white, western bodies as "normal") is a theme we will return to.

## 2.2 Women's Health Meets HCI

But throughout all of these histories (and discourses), questions of technologies and devices have been present. Returning to the self-help clinics we see the "iconic tool...the cheap plastic vaginal speculum" [137]: a cost-effective, widely-distributed *and technological* instrument for examining and familiarising oneself with one's own anatomy, demystifying it and moving power over health from medical practitioners to the patients [137]. The home pregnancy test, originally prescription-only in North America, provides another example of technology's central role [42]. More recently, one can point to the internet and other developments in information technology that have made

health-care information available to women who would not previously have been able to access it as conveniently, or at all [145].

HCI, as a *sociotechnical* field, is thus always already implicated in questions of women's health—and so it is of no surprise that the field would turn to study health and gender. If anything, it is surprising that it took so long; we find ourselves agreeing with Almeida et al.'s hypothesis that the field's gender bias and society's discomfort with the sexual played a role in HCI's previous silence [9]. Motivated in part by feminist HCI [22, 150] and the “somatic turn” [122], researchers have now turned to study and engage with questions of women's health. The subfield is not a large one, but it is growing, and we are excited to see more and more researchers turn to it as a site of work, activism, and involvement.

In that, we need to collectively be mindful that technologies of women's health frequently carry with them particular notions of embodiment, health and womanhood—not intentionally, but inevitably. As we know from feminist technoscience [184], the social and technological are mutually shaping of each other: existing notions of what “women's health” encompasses alters which technologies are designed within the movement, and for whom; existing technologies reshape the social sphere, both directly (by opening or foreclosing different avenues of participation for different individuals) or indirectly (by provide examples, hints and cues as to what the “technological imaginary” of women's health should be [55]. To return to the example of the speculum; that the nature of the speculum (cheap) matters is not just directly relevant because of the implications this has for who can access it, but also because of what it communicates “women's health” should assume (the presence of a vagina) and who it should be for (community-embedded individuals, regardless of class).

### 3 DISCURSIVE DEBATES IN WOMEN'S HEALTH

While the women's health movement engages in both reformist action to improve the medical system and radical action to replace it, it also engages in *discursive* action: the creation of discourses. By this we mean, as Foucault put it, an “institutionalised way of speaking or writing about reality that defines what can be intelligibly thought and said about the world and what cannot” [68]. Discourses work to create community through establishing shared understanding and terms of meaning; they set the bounds and goals of a space, a conversation and a movement [30]. In the case of work on women's health, we would point to the meaning of “women's health”: to collaborate in a functional way, members of the community must have at least tacit agreement on their definitions of both words individually, and of the term of art overall. What this meaning is differs in different times and contexts, as cultural dynamics shift and grow; there is no singular “correct” definition to be teleologically sought for.

#### 3.1 Defining “Women”

Many definitions of womanhood, health and the overall discipline play into the notion of “women's health”: as Kuhlmann puts it, the sites of women's health activism—stemming in part from its discursive construction—are “characterized by tensions and, in part, even contradictory interests” [114]. In the case of *women*, there are multiple definitions and multiple theories, some of which are summarised by Kuhlmann and Babitsch, and (in a slightly-overlapping one) the work of Cook [46, 115]. Taken collectively, they highlight two major threads *essentialist* and *postmodernist* discourses of womanhood.

An *essentialist* idea of womanhood assumes that “woman” is a fixed, biologically-oriented category; that women (and their societal concerns) are anatomically-related or derived in nature. This view was particularly common in Marxist–Feminist approaches to feminism in the 1960s and 1970s, and can be exemplified in Marieskind's statement that “The oppression of women is

derived from her ‘womanness’: her biologic differences and her ability to bear children. These differences have been used to build social structures and a supportive ideology of female submissiveness” [126]. This view of womanhood as a natural, biological and primarily-reproductive category explains much of the early work in women’s health, which focused on concerns around access to (and the nature of) reproductive health services. But it has been strongly critiqued, for good reason: an essentialist view (even one that is “feminist” that *inverts* the gender binary) legitimises and reinforces it, as does the idea of a universalised, singular experience of womanhood. In both cases, the theories that fall under the umbrella of essentialism leave many women out in the cold; a “natural” view of womanhood is silent on questions of gender’s contextual nature, or genders beyond the binary. A singular experience of womanhood “grounded...on the predominately white middle class women active in the feminist movement in the early 1970s” [89] has no space for the ways that womanhood, and patriarchal oppression, are experienced differently by queer women, poor women, trans women, women of colour and women surviving (or not) in different patriarchal contexts and gender regimes.

A *postmodern* idea of womanhood attempts to “break open [the] ongoing naturalizing discourse” [114]; to avoid falling into the trap of legitimising the idea of womanhood as a fixed, “natural” category and instead identify womanhood as a concept that is discursively constructed in different places, at different times, for different people. To postmodernists, womanhood is a fluid and contextual concept; there is no universal concept of “womanhood” but instead different experiences of the world based on one’s situatedness, of which gender is only one of the (direct) factors. Postmodern approaches to womanhood allow for a far-more inclusive framing of both the oppression that women face, and the oppression those subject to the concerns traditionally raised by the women’s health movement face, while understanding that those are not uniform or perfectly overlapping populations. Queerness, disability, race, class and the legacies of imperialism can be factored into discussions of womanhood, in a way that does not relegate them to being “additive” to some universal idea of gender. In turn, postmodern approaches have been criticised for “lacking the language to speak in solidarity and collectivities” [46]. If there is no universal womanhood, how can there be a women’s movement?

Universalism produces a notion of shared community; insiders who can work together in achieving shared goals. But at the same time, it produces outsiders. When the site of community is “health”, this alienation renders populations not represented within some artifice of “universal womanhood” invisible within research and vulnerable within medicine. Discussing this tension, multiple researchers conclude that the solution is a certain degree of uncomfortable “fence-sitting” [89, 115]. McCormick et al. in particular, despite coming from a position *against* essentialism, advocate postcolonial feminist Spivak’s “strategic essentialism” [169]:

*“Since one cannot not be an essentialist, why not look at the ways in which one is an essentialist, carve out a representative essentialist position, and then do politics according to the old rules whilst remembering the dangers in this?” [95]*

In other words, while a certain degree of essentialism is necessary, it is the responsibility of scholars engaging in it to do so *consciously*, making explicit who their framing leaves out and the ways in which it is insufficient and must be expanded upon [89]. Researching uterine cancer under an essentialist frame would constitute assuming that “woman” and “has a uterus” are the same population. Researching uterine cancer under a *strategically essentialist* frame would entail recognising that (for example) many women have had hysterectomies or do not have uteri at all, while many non-binary people and trans men do (with different possible risk factors), attempting to design the study in such a way that those populations and their concerns were included and



discussed.<sup>3</sup> In the absence of being able to do so, researchers would be explicit the limitations and urging further research with those left out. In design contexts (be they process, interaction or software), where more flexibility is possible, researchers and health-care workers would work to ensure explicitly-inclusive processes that factor in population differences around terms of address, gendering and identity [173].

### 3.2 Defining “Health”

Similar debates and discursive divides exist around the question of “health” and how it is defined—debates that often overlap and resonate with questions of essentialism (specifically, questions of biology). Early, normative phases of the women’s health movement framed health as a distinctly bodily concern: the “medicalization of the natural physiological processes in a woman’s life and the exclusion of the social context of the woman’s life within which her experiences of health are constructed” [130]. Reformist concerns focused on direct bodily interventions; getting the pain women experienced, or conditions which disproportionate them, taken seriously within the medical establishment. More radical concerns worked on, as discussed, the provision of direct biomedical interventions outside of established medical regimes, or knowledge of one’s own body.

Once gender is no longer considered essentialised and biological, there is room to consider the world *outside* the body, and the medical facility—how the way gender is played out in wider society acts to create different health concerns—and correspondingly examine how health problems for women come to be in the first place. An example is the work of socialist feminist Lesley Doyal, using the United Kingdom as a case study. In particular, she highlighted the way that *gendered divisions of labour* created the conditions that brought women “into the orbit of the health care system” [54]. Women were (and are) more likely to engage in domestic work, and less likely to have jobs outside the home. Correspondingly a different range of exposures and health concerns arise, including household chemicals and garden substances, isolation-induced depression and exposure to domestic violence through the vulnerability that curtailed income and independence induces. Similarly, the structural misogyny found in employment produces disproportionate over- and underrepresentation of women in particular industries and roles, with corresponding disproportionate risks, and exposure to assault and harassment in working environments.

These differing definitions of health, combined with the differing definitions of womanhood, have produced a plural and shifting discourse of “women’s health” and the boundaries of what can be found and imagined to fit within it. Ideas of “women’s health” as biomedical and essentialist focus on “reproductive functions” [188]; biomedical interventions around conception, contraception, childbirth and overall gynaecological health, through a “one size fits all” lens. Completely inversely, a social, postmodernist framing would instead look at the vulnerabilities of people classed as “women” within a particular societal context, and the health consequences thereof. Such an approach would alter drastically depending on the context in question, and the aspect of health being examined.<sup>4</sup>

### 3.3 Exploring HCI’s Discursive Framings of Women’s Health

These debates occur within a domain frequently seen by its occupants as feminist in nature, raising wider questions about the nature of feminism (and its consequences). The discursive framing taken

<sup>3</sup>The idea of recognition as an improvement or reform is also commonly mooted, but we are cautious about treating recognition as sufficient; as radical activists in feminist, indigenous and/or queer circles have frequently demonstrated, “recognition” can serve a normalising purpose that legitimises inequality, as or more frequently than it serves to legitimise the needs of marginalised populations [47, 72, 164]. When seeking material changes in outcomes, we prefer to seek material changes in the processes producing them.

<sup>4</sup>For more on differing frames of womanhood and the (political) consequences thereof, see [149].

has substantial implications for who (and what) is included within the work of women's health research. Discussion of this has mostly occurred within traditional fields of research. But with the move of HCI researchers to examine women's health, we are required to take a critical and reflective feminist lens and ask: What discursive formations has HCI been using on these topics, and what are the likely consequences?

**3.3.1 Framing Our Analysis.** Before we begin this analysis, it is worth being clear about two vital things to bear in mind. The first is that there is no "perfect" feminism, and we are not looking for one; as Murphy's [137] technoscientific work on women's health indicates, the question has always been one not of feminism but of sometimes-contradictory *feminisms*, held together in a productive tension. Consequently, it would be hypocritical (not to mention, hardly feminist) for us to treat any group of researchers (including ourselves) as capable of reaching any utopian feminist perspective. We are all fallible, existing in a movement that is ultimately not just contradictory but frequently iterative. There are many places where the framing used in particular papers is exclusionary, essentialist, or appears lacking in nuance—but nuance is not always politically possible, hence the existence of strategic essentialism as a tactic [169]. Further, to take issue with scholars for not incorporating all populations or all scholarship would be to require of researchers the very "god trick" feminist epistemologists often critique. Our work is not intended to denounce people, or be taken as a tearing-down of researchers; we highlight the work of individual papers and their authors only as illustrative examples of the overall discursive frame. This highlighting is not to look backwards, assigning blame, but to look forwards, posing generative opportunities for future research and/or design [22].

We argue that "women's health" needs to include non-essentialist notions of womanhood and health, respectively. As our histories of the women's health movement have shown, questions around the consequences of racially silent (and so implicitly white) approaches to health, or disability-excluding approaches, are nothing new. Feminist work needs to question the abled, cis white body as its singular and unmarked subject of inquiry, and it is feminist to trouble and discomfort such work where we find it [5]. Again, such troubling should not be read as personalised—as finding individual authors *guilty*, or *liable*, for past harms. Rather, as Young advocates [196], it should be taken as a solicitation for communal *responsibility*: for us to, collectively and individually, do better than perpetuating normatively established harms in the future and actively and collectively work to find ways of being accountable to those we inadvertently come to harm.

**3.3.2 Methodology.** With that framing in mind, we sought to investigate the way that the term "women's health" is framed in HCI. Specifically, we wanted to understand how work self-described by its authors as "women's health" research approaches questions of gender, health and gendered health. We searched abstracts, titles and keywords of publication in the databases of the ACM Digital Library Guide to Computing Literature as well as the IEEE Xplore Digital Library. In both cases, our search terms were ("women's health" OR "womens health" OR "womens' health"). With our focus on HCI, we limited the search of the ACM Digital Library to SIGCHI-sponsored publications and events. Similarly, for the IEEE library, we added AND ("HCI" OR "Human-Computer Interaction" OR "Human Computer Interaction"). Any paper that met the search parameters was then read to ensure that it directly engaged with the topic by the first and last authors to ensure that the self-naming matched expectations. This was the case for all papers. This evaluation was undertaken in parallel, with discussion when the evaluators disagreed, and resulted in the single IEEE paper which met the search criteria being excluded, as it is a general medical imaging paper that contains neither the term "women" nor "human" [187]. Hence, our results are restricted to

Table 1. The Corpus of “Women’s Health” Papers We Draw On

Paper	Year	Venue	Technology Context
Alqassim et al. [12]	2019	CHI LBW	Facebook (Pregnancy Loss)
Almeida et al. [11]*	2016	CHI Interactivity	App and Wearable for Selfinspection
Almeida et al. [10]*	2016	CHI	App and Wearable for Selfinspection
Almeida et al. [9]	2016	CHI	None (Ethnography on Incontinence)
Andalibi and Forte [14]	2018	CHI	Social Network Sites (Facebook, Pregnancy Loss)
Balaam et al. [19]	2017	CHI Workshops	None (Re-appropriation of Classical Technologies)
Bardzell et al. [21]	2019	CHI	None (Design Frames for Menopause)
Bellini et al. [26]	2018	CHI SIG	None (Feminism)
Campo Woytuk et al. [39]	2019	CHI LBW	None (Design Sketches around Menstruation)
Epstein et al. [61]	2017	CHI	Menstruation Trackers
Gui et al. [82]	2017	CSCW	Online Health Communities (Pregnancy)
Homewood [93]+	2018	CHI DC	Selftracking for Menopause
Homewood [94]+	2019	CHI alt.chi	Selftracking for Menopause
Lazar et al. [117]	2019	CHI	Social Network Sites (Reddit, Menopause)
Prabhakar et al. [146]	2019	CHI SIG	None (Global Pregnancy and Beyond)
Schneider et al. [158]	2019	CHI	Fertility Tracking Applications
Søndergaard and Hansen [163]	2018	DIS	Digital Personal Assistants
Trujillo and Buzzi [177]	2018	UMAP Adjunct	Menopause Selfcare Intervention

Publications with a \* or + symbol attached belong to the same project.

*Abbreviations:*

CHI – ACM CHI Conference on Human Factors in Computing Systems

CSCW – ACM Conference on Computer-Supported Cooperative Work and Social Computing

DC – Doctoral Consortium

DIS – ACM Conference on Designing Interactive Systems

LBW – Late Breaking Work

SIG – Special Interest Group

UMAP – ACM Conference on User Modelling, Adaptation and Personalization.

the 17 entries in Table 1<sup>5</sup>, all stemming from the ACM Digital Library as they were available to us in May 2019.

There are some limitations to such an approach; for example, we intentionally limited ourselves to the term of “Women’s Health” and its variants, and so excluded work which (while focusing on areas that would, in a traditional understanding, fall under the umbrella of “Women’s Health”) does not use the term. But this produces a looping problem; searching for those topics would involve reshaping the corpus in line with what the authors consider to fit under the field, and so represent the authors’ expectations more than it would the community’s. Using the term of art in isolation—a term of art used, after all, in the framing and call for proposals of this special edition—allowed us to more generally investigate what *HCI researchers as a whole* self-describe as “Women’s Health” research. In that, we did not conduct an expansive search of cited and citing work that might feasibly address topics of interest as well, to stay close to the works that explicitly position themselves within this conceptual notion. As our corpus demonstrates, the term “Women’s Health” is comparatively young in HCI: we are unable to find a paper prior to 2016, when the term was first used in work by Almeida et al. [9, 10]. It has slowly gained traction since, and appears to be accelerating: although we only conducted the search in May 2019, 2019 was still the year with

<sup>5</sup>Notably, one paper [26] lists Katta Spiel as a co-author, making this critique not just one that is oriented outwardly but very much also applies, at least in part, to our own previous engagement with the topic.



the highest number of papers (7 of the 17 total). We deliberately stayed in the context of computer science related work—excluding, for example, investigations in the areas of more media and design focused venues—to focus on technologically driven publications on the topic, even if they might not discuss a specific technological context. Six of the papers fall into this category, eight concern themselves with mobile applications (five of which are trackers) and the rest is largely concerned with (self)-representation and communication about identified issues in social networks and online forums. More exploratory designs are presented only in initial design stages.<sup>6</sup>

For our critical discourse analysis [98], we understand the publications as *texts* that can be analysed along *statements*, *syntax* and *semantics* [35]. A particular focus lies on the limits of what can be said [66], another on the limits of who might say them [69]. Our analysis is undertaken with an awareness of our standpoints [88]—as a collective of authors who are white, feminists, highly educated within a Western epistemic context, and mostly disabled and/or trans. Our reading and our subsequent critical analysis are influenced by our lived experiences as people who trouble fixed binaries of male and female, disabled and able-bodied [174], but also, we recognise, as people who are otherwise supported within the epistemic and material legacies of colonialism and race. To further contrast our readings of the core corpus texts, we draw on critical works in other fields concerning a topic at hand (e.g., what makes a “woman”). Themes for the critique were established through collective inductive coding.

Within HCI, discourse analysis has been used to investigate the discursive elements of environmental discourses in HCI [80], understand how HCI’s concept of ageing impacts what can be researched how [183] or delineate discursive shifts (e.g., from “user” to “maker” in [151]). Some of the authors have experience in using discourse analysis in similar [166] and different [165] settings. As an approach to analysing the discourses surrounding “Women’s Health”, discourse analysis has been identified as a useful tool within Science and Technology Studies [123]. We undertake this study because the discursive debates we refer to, despite drawing from theory, are hardly theoretical; they cut at the core goals of women’s health activism, and have drastic consequences for the trajectories of peoples’ lives. Medical research, for example, that seeks inclusive change but takes an essentialist viewpoint remains silent on (or, treats as of secondary importance) health concerns that are not universal and/or biologically rooted in a particular idea of “women”. Correspondingly, it is silent on the consequences that medical heteronormativity has for lesbian and bisexual women [130, 131], the way that poverty, race and the legacies of colonialism produce oppressive medical experiences for indigenous and immigrant women [36, 129], and how the essential linking of biology and gender leaves non-binary people and trans men with reproductive health needs (as well as trans women with needs that *depart* from “universal womanhood”) invalidated and vulnerable to worse medical outcomes [2, 25, 76, 87, 161].

Concretely, after selection, Keyes conducted an initial reading of the corpus to familiarise themselves with the corpus and identify the types of publications in it and their general context (see Table 1). In our reading, we were used lenses on the models of womanhood and health with additional questions on disability, sexuality, class, cultural, race and trans implications as well as a question into the conceptualisation of health as individualised or collective responsibility to understand how dominant discourses of “women” and “health” weave through and articulate themselves in this corpus and which consequences this entails. Reading the corpus by tracing a set of shared questions of interest allowed us to understand different perspectives on *power and status* as is relevant to pursue our critical goal [118]. Keyes, Williams and Spiel individually engaged with the papers along these notions. Spiel added notes on technology, purpose, participants and envisioned experience as additional lenses to their reading. In text and video chats, we collectively established

<sup>6</sup>A critique that, arguably, also applies to this article.

the main strands of our analysis. In writing, Williams was responsible for Section 4.3 and Keyes did the initial draft on the remaining sections. Spiel then provided feedback and editorial guidance on the presentation. As with any discourse analysis, the process relies on our shared interpretation and the negotiation of a range of perspectives. However, in this continued negotiation also lies the strength of the approach in that we gained a deep understanding (and appreciation) for what the growing field has achieved so far and how it might go further.

## 4 HCI DISCOURSES OF WOMEN'S HEALTH

Our analysis focuses on the frame that HCI work on “Women’s Health” uses around *health* and *womanhood*. We begin by investigating notions of health; what topics are absent within the corpus. Subsequently, we examine questions of *womanhood*, beginning with an inquiry into how womanhood is treated as embodied (or not). Drawing on positions from Critical Disability Studies, we then turn to how disability is made known within the framing used; we finally investigate discursive *silences*, where a lack of attendance to class, race and sexuality open up a different, but no less dangerous, set of risks.

The concerns and axes of marginalisation or aspects of embodiment that we cluster or separate reflect not an evaluation of importance or how much there is to say in an idealised world. Instead, they represent a mixture of what we can see from our own standpoints as researchers (with some of us drawing on our own lived experiences as queer, trans and/or disabled individuals), and the depth of material that touches on these concerns within the papers we are analysing.

### 4.1 Discourses of Health

The women’s health movement, as discussed earlier includes multiple perspectives and debates on the concept of health. One debate is around whether to prioritise biomedical views of health, which centre the authority of the clinic [67] and the woman as patient and subject, or social views of health, which open up space for communal action, health and ownership of self. Taking a social perspective also enables a focus beyond the immediate embodied pain or harm, reeling back to examine the *sources*: a social view of domestic violence, for example, involves not only medical care on terms that centre the victim rather than medical infrastructure, but also investigating and attempting to resolve societal causes.

HCI work explicitly situating itself as relating to women’s health sits between these two positions. Many papers do recognise that social factors appear in medicalised frames; Bardzell et al.’s “(Re)-Framing Menopause Experiences” is a good example of that, working from an understanding of menopause as “an era of life qualified not only by diverse physiological changes, but also by changes in social, sexual, and even self-relations” [21]. Understandably, for a field of *sociotechnical* researchers, social factors often make an appearance in design decisions or methodological approaches and framings.

At the same time, definitional work around women’s health tends to take a much more rigid form: Almeida et al.’s “HCI and Intimate Care” opens by articulating the position that:

*Women’s health tends to be defined as health issues and problems if they only affect women, or if these issues/problems are more prevalent or severe among women. Under this definition women’s health will include issues such as menstruation, and menopause, through to cervical cancer, sexually transmitted diseases and pregnancy.* [9]

The work that Almeida et al. undertake in that paper is important; health issues that “only affect women, or...are more prevalent or severe among women” are underconsidered in both biomedicine and HCI interventions into health. But there is a limitation to the frame: it matches not wider

notions of health but Weisman's definition of a "reproductive functions" approach to women's health—one that is ultimately both biologically-essentialist and as a consequence reductive [188]. There is nothing wrong with individual papers taking such a position; *all* frames, by definition, define certain concerns as outside their remit. The issue is when it becomes ubiquitous. Much work in this vein mirrors this definition, focusing overwhelmingly on "reproductive functions"—genital awareness, menopause, pregnancy, miscarriage and menstruation.

As a consequence, this constrains the view of *what* social factors, and which health phenomena, should be investigated and considered. Considerations of other health conditions that "are more prevalent or severe among women" due primarily to social causes provide an opportunity for future research, including health difficulties caused by disparities in employment rate and types of labour, for example, as studied by feminist labour scholars; the implications of disproportionate domestic work being placed on women in heteronormative contexts, or of emotional and "body work" that appears within feminised work contexts [54, 57].

Beyond "reproductive health" as a concern of women's health, future work could, for example, broaden its focus out to examine human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS), or sexually transmitted diseases—particularly as current HCI work which *does* investigate HIV does not consider itself part of women's health. One potential explanation comes from the specific frame of womanhood that women's health research deploys (as discussed below), in combination with stereotypes about the nature of HIV; that it is a disease for queer people, predominantly queer men. In reality, precisely *because* of the way these stereotypes permeate public discourse, and the resulting stigma [154], disease transmission has been incredibly common in heterosexual, white, middle-class relationships for decades [13, 91, 142]. Driven in part by the stereotyping prevalent in sexual health research, trans women—particularly trans women of colour—have found themselves vulnerable and undersupported since the beginning of the AIDS crisis [20]. A perspective on women's health focused on disproportionate health concerns should, by all accounts, consider the underrecognition and consequential undersupport of women with HIV to fall easily within its bailiwick. It is not just what is part of our corpus, but also what remains chiefly outside of it. In other words, we should be concerned about what an implicit or explicit alignment of "reproductive health" with "women's health" means for the tackling of women's health concerns which fit uneasily within a frame of "reproduction".

A similar potential lies in the consideration of social factors around intimate partner abuse, which disproportionately impacts women. While "Hacking Women's Health" accurately and thoughtfully notes the "darker" side of women's health, specifically sexual violence and harassment (physical and emotional experiences with decidedly social causes) [19], no HCI work on this self-describes as "Women's Health". HCI features excellent research on both sexual violence and sexual harassment, but it is (in practice) treated as distinct. This has potentially profound consequences, as it means that while researchers are undertaking their work conceptually aware of concerns around violence and harassment (and how technology enables, or forecloses, its possibility), these concerns are not centred while designing or investigating software platforms that frequently open up new possibilities for relating and, consequently, new possibilities for harm. We need to collectively reflect on what it means for us to advocate health integrations with FitBits and other quantified tracking tools without considering the phenomenon of "peer surveillance", and the way that technologies can enable vulnerability to abuse [192]. The obligation to reflect is not, of course, solely on researchers working within women's health—a failure to consider surveillance practices is far wider within HCI—but given the feminist framing of work in this area, it seems an opportune place to go further.

There are reasons for optimism: many authors do *note* the social frame, and in the case of the Bardzell et al. [21] and Lazar et al. [117] works, adopt it. And as we have referenced, there *is*

some fantastic research on the (frequently gendered aspects of) abuse, violence and harassment; however, some works do not consider themselves part of “women’s health” research. The same is true of the myriad other social factors in health; is medical bias itself as “health issue” under this frame? If exclusive frames of health are taken, the consequence is an artificial narrowing of the work that can be done—something that risks becoming a circular problem that is harder to resolve the more work subscribing to “Women’s Health” operates from within this paradigm.

#### 4.2 Gender, Sex and “Womanhood”

Given the standpoints of the authors—many of whom are trans and/or otherwise queer—one of our earliest sites of examination concerned how HCI work on women’s health constitutes questions of biology, gender and/or sex in relation to “womanhood”. Recalling the various models of womanhood found within wider discourses of women’s health (see “Defining *women*”, above), we expected to see a wide range of definitions and approaches. Interestingly, most papers did not explicitly work to define womanhood or women within the scope of their work, instead relying on either contextual information (anatomical dependencies of the system being studied, for example, or how the paper describes the authors’ assumed user) to communicate authorial intent. Relying on these cues, we identified three different approaches to the gendering of bodies and the anatomical embodiment of womanhood. These indicate different levels of attending to a diverse range of lived experiences versus tying womanhood to a narrow set of biological markers.

Some works are explicit that their understanding of women’s health features a biological root of womanhood that necessitates a one-to-one match of “woman” and “uterus”. An early example—one that played an important role in establishing the urgency of women’s health research in HCI—is Almeida et al.’s work on “Labella” [10, 11], an augmented reality system to support pelvic fitness. This is very much in the spirit of earlier educational projects about embodiment, such as the speculum workshops run during the 1970s, and adroitly demonstrates one of the important ways that HCI researchers can work towards challenging medical inequality. But at the same time, the one-size-fits-all biological framing of womanhood raises some issues: it means the work assumes all women to have “female external genitalia”, that this external genitalia takes a single consistent form, and that people with a vagina are the only ones who would benefit from pelvic floor exercises, whereas people with a penis can find them equally useful. Other work, such as Schneider et al.’s “Communicating Uncertainty in Fertility Prognosis” and Homewood’s “Inaction as a Design Decision”, cautions against biological essentialism and generally displays a thoughtful and insightful approach to issues of identity and embodiment, but still consistently maps gender to anatomy when describing engagement with pregnancy and menstruation [94, 158]. Similarly, a prior work by some of the same authors refers to “people who identify as female” as experiencing menstrual cycles, pregnancy and menopause, in contrast to “those who identify as male” [93]. This use of identity-oriented language while discussing biological phenomenon simultaneously cautions against and engages in equating gender (or “identity”) and biology.

Other works more-explicitly recognise and discuss the existence of trans and intersex people—specifically people with uteri who are not “women”, and people who are women but do not have uteri—but this recognition is often inconsistent. Woytuk et al.’s “Your Period Rules” [39], an important paper on period-positive technologies, uses the framing “people who menstruate” rather than “women” to describe workshop participants, recognising that the two populations are not one and the same. This recognises and affirms the existences of trans bodies and their presence within the domain of women’s health. But at the same time, the rest of the article refers to “a woman’s body” as the site of menstruation, and exclusively use “she” to describe their participants or hypothetical users. Epstein et al.’s “Examining Menstrual Tracking” acknowledges that

“not all people who have a menstrual cycle identify as women, and not all people who identify as women have a menstrual cycle” [61]. Yet despite that, “we use the gendered term ‘women’ in this paper...this follows the general use of the term ‘women’s health’ in the HCI community”. In this they are followed by Lazar et al.’s “Parting the Red Sea” [117], which explicitly points to “Examining Menstrual Tracking” as the inspiration to refer to those who have menstrual cycles and menopause as women.

Some of our questions can also be found in the framing document for Balaam et al.’s “Hacking Women’s Health” workshop, which asks “when we say the female body, [do] we mean simply cisgender women, or technologies that might be used by men, other genders, whole families or communities?” and gives us reason for optimism and faith in community—we see, in those questions, signs that the community of researchers working on these issues are themselves concerned about and aware of ways to do better [19]. This framing of questions of gender and health is (on the surface) avoidant of essentialising: it recognises the existence of genders outside the binary, and a detachment between gender and anatomy. But at the same time, the definition of “woman” remains implicitly mapped to “cisgender women”—trans women do not make an appearance, even in this questioning of the gender binary and implicit single-gender focus of “women’s health”. Transmasculine people, whose biomedical concerns may strongly overlap with those of cisgender women, are treated as either (anatomically) folded into “cisgender women” or (linguistically) simply part of “men [or] other genders”. This questioning, while well-intentioned and very much ahead of the broader corpus (whatever its limitations), also makes an appearance only in a section on “feminist speculative design”, treating the existences and health needs of trans bodies as future hypotheticals, rather than materially-consequential realities. A critique that could arguably also be made for the speculative designs in this article.

In sum, then, there is not a consistent approach taken within this work to the ties (or lack thereof) between gender, sex and/or anatomy. To be clear, we would not expect there to *be* a consistent approach; as evidenced by the debates within women’s health more broadly, there are a range of positions with a range of arguments for and against their use. But what surprised us was how narrow this range is within the HCI works: how, even when explicitly recognising a range of gendered and/or embodied forms beyond a simple binary, work frequently fails to engage with those forms in depth. We did delight in the recognition when it came, recognising (in return) a desire to do better and see beyond, and recognising in the diverse approaches taken in these papers (diverse even when the authors matched) a general trajectory of growth and learning. But at the same time, it is clear that more is needed.

We highlight this need for more growth because of the urgency of resolving (even well-intentioned) exclusions. There are a range of major negative consequences of the (frequently constrained) approaches currently taken. The first is discursive: What example are we setting to each other about what work should we done, and what work fits here? As evidenced by Lazar *et al.*, drawing on the frame set by Epstein et al., research that takes a particular position on embodiment bolsters that position. Despite a lively and progressive debate within women’s health more broadly [173], it is to *each other* that we are looking for how to shape our work. When our work collectively creates and depends on a narrow frame of womanhood, this makes likely a somewhat looping cycle in which we struggle to do trans-inclusive work because of how deeply-seated implicit assumptions about the scope of the subfield become.

Second, the discourses we adopt have already had consequences for our participants, and for our research practices. Let us return to Epstein et al. [61], which recognises the existence of trans bodies—and includes trans participants—but also works to fit itself within the frame of gender and embodiment that “women’s health” takes in HCI more broadly. The result is a article that uses “women” throughout—despite soliciting *and recruiting* participants who are not women—and



so correspondingly treats the experiences of trans men and nonbinary people<sup>7</sup> as “women’s” experiences. The result is an overwriting of those participants’ identities and experiences. In the language of feminist epistemology, this is an example of epistemic “injustice” or “violence” [102, 170]; a statement that the researchers know participants’ gender and self better than they do. In a domain working to model itself on feminist principles, this is a dangerous methodological example to set. Again, we do not highlight individual works in order to cause harm to the authors or denigrate the great value of many of these projects, but to evidence a wider concern we wish to flag and hope to see people avoid perpetuating in the future.

Finally and most materially: What does it mean for the ability of trans and intersex people to participate in and use technological shifts in health care if they are assumed not to exist, and erased should they assert themselves? Even when there is goodwill illustrated, the papers in our corpus veer towards a model of womanhood that either reduces it to a specific biological makeup of the body, or attempts to merely graft trans and intersex lives onto an otherwise-essentialist model of gender—one largely retained despite that attempted graft. By doing this, current work in HCI on women’s health is resonant of the early years of the US women’s health movement, which (while rejecting the notion of the cis male body as an unmarked norm) frequently did so through advancing an essentialist and monolithic vision of womanhood. In the case of research within our frame, this appears as an over-focus on a simplified and static idea of gender and embodiment that erases trans and intersex people and their health needs. This erasure is not merely an issue of rhetoric—it is inherent in the framings, population choices (including the reporting on them) and design choices which will result from essentialist research.

That is to say, HCI health researchers must consider the concrete harms their research and design implications may contribute through reifying exclusionary discursive frames. The absence of transmasculine and/or non-binary people who become pregnant, for example, mimics issues in medical research and practice more broadly [168]. The (many [121]) non-women with uteri are already erased and discriminated against in wider gynaecological and women’s health practices, precisely due to the fields’ singular and essentialist idea of patients’ embodiment and identity [41, 92, 140]. This medical neglect results in layers of emotional and physical harm to trans people with uteri. Shame and dysphoria, fuelled by essentialist notions of women’s health, cause trans individuals to avoid seeking treatment for common and painful health concerns, even those as seemingly-mundane as urinary tract infections [133, 189].

Such neglect is not surprising; the practices and discourses of medicine more generally discriminates strongly against trans people. On the theoretical and discursive level, Singer points to the long history of “locating the sight/site of deviance on the bodies of a wide array of social outcasts” [162], and the way this leads to even the *visual* representations of trans people in medical textbooks situating trans bodies as atypical, “deviant” and less-than-human. This is part of a medical education system that (in Canada, as an example) spends an average of 5 hours of medical school on LGBTQIA\* health care generally [139], much less trans health care or trans-competent practices specifically. The result is medical practices which discount the existence of trans lives and bodies, which (played off against higher rates of poverty and other forms of societal discrimination) results in a drastically reduced life expectancy for trans people, particularly trans people of colour [108]. This circular loop—trans people being erased, not being taken into account and fading from view, justifying the erasure—is a closed one. It cannot be broken but for interventions into the sociotechnical processes of healthcare which include, rather than discount, trans existences [25].

<sup>7</sup> As reported along self-identification within the article.

Our point in all of this is not to hold HCI researchers working in women's health responsible for trans-erasing medical care, or its consequences. Instead, it is to situate the absence of trans lives in this work in its context: that of a society and medical system that already trends towards discounting trans existences, with correspondingly fatal consequences. If the purpose of women's health work in HCI is to—through technology—address the historic underrepresentation and erasure of gendered bodies, identities and trajectories in medical practices, it must be careful to not perpetuate some of the very systems it attempts to tackle. Or, how Fox, asserts: "Power is found in the deconstruction of menstruation, Gonzalez urged. A move that would involve decoupling the bodily process from its tight association with womanhood and femininity" [71, p77]. One approach is to simply take a more nuanced and affirmative understandings of pregnancy and birth. Similarly, the concerns around genital structure awareness, health and hygiene that several HCI papers in this discipline locate for cisgender women [9], are also concerns for trans women [181] and intersex people. Intersex people particularly have long experienced drastic ignorance, stemming from a lack of awareness and concern, in medical environments [8], resulting in a harrowing rate of infant genital mutilation for those whose bodies do not conform to traditional notions of "male" and "female".

Rather than continue situating these bodies outside the frame of health care (and of womanhood), work in this area could seek to address informational absences in a more nuanced way, considering the diverse range of embodiments a technology for "women" may be placed in conversation with, and the diverse range of identities an anatomically-fixed technology will encounter. If we are designing or assessing the use of online resources for medical information, for example, we might consider looking at how this is a practice trans people are regularly forced to engage with, even when gynaecological care is (officially) "available" [152, 171]. Beginning this conversation offers an opportunity to, as Hanssman puts it, "trans" biomedicine: "introducing radical contingency with respect to sexed or gendered bodies and their need for clinical care" [85]. Philosophically, such an attitude is not entirely distinct from existing work on women's health—in many cases they embody the same desire for health-care *form* to be contingent on need, rather than health-care *availability*. Correspondingly, we offer these analyses and proposals not as an alternative to but as a potential future for women's health research.

### 4.3 Conjuring Hysteria, Erasing Disability

In our analysis of the corpus through a disability studies lens, we identified the following two primary themes that operate in tension with each other: the production of *menstruating bodies as disabled* by virtue of their difference from cis-male bodies, and the *erasure of disabled people's needs* concerning gendered health. Many researchers conjure the stigmatic link between femininity and madness—often manifested by the uncritical reproduction of patient testimony that reflects states of distress. While these states of distress are painful to experience, they can also be attributed to internalised ableism [38] and misogyny rather than seen as natural to the menstruating body. Internalised oppression is defined as those beliefs toward ones-self that reflect harmful attitudes the surrounding culture has toward ones' in-group [51].

Oppressive frames can be reproduced even and especially within feminist projects [156]. Schalk explains that "ableist metaphors of disability limit the scope of, and contradict the goals of, the feminist arguments in which they are used because these metaphors are neither innocent nor value neutral, but ... implicitly political in character". Researchers in HCI need to mind their metaphors to protect the dignity of their participant populations. By presenting examples of participant testimony, our purpose is not to use the participants' words against them. Instead, we want to encourage researchers to provide such testimony embedded in the critical analysis of cultural contexts.

Otherwise, they might risk inadvertently deploying participants' perspectives as further violence against that population.

For example, Epstein and Woytuk both allow participants' own testimony to reproduce narratives of the menstrual cycle as "crazy-making", a time of irrationality and unreliability [39, 61]. For instance, one participant is quoted saying, "I'm really emotional and irrational and I can look at my tracker, see that my period is due in a week or less and chill out and realize I'm PMSing instead of having real feelings" [61]. Such a distinction between "real feelings" and being "emotional and irrational" then tie not only into a notion of describing premenstrual syndrome as a state of deviancy [198], but additionally echo hegemonic epistemological conceit that emotional engagements are incompatible with knowledge production [99]. Without questioning these internalised oppressions, either directly with participants or within the discussion of findings, the authors tacitly, even if inadvertently, legitimise rhetorical tropes of femininity and hysteria [60].

Similarly, menopause is often uncritically presented as a condition that inherently reduces health rather than as a common state of ageing. Machine-learning approaches are envisioned to "fix" the gaps in menopausal health care (e.g., [177]) without reckoning with the social and cultural factors that have lead to the erasure, neglect and dismissal of menstrual and menopausal health in contemporary Western medicine. In such narratives, menopause is experienced as a loss rather than a life stage: a loss of reproductive capacity, which is inherently tied to social value and status even when a person does not want to reproduce; and as a loss of sexual faculty (see also, [199]). Menopausal participant testimony is used to deploy narratives of disembodiment—of the body snatcher, the invasion of madness and the loss of self through age or impairment.

Lazar et al. present menopausal testimony of "waking up in another person's body", having a "raging beast" inside or "being hijacked by an alien" [117, p6]. These experiences of self-alienation are related to social stigmas against mental illness and disability [198]. These experiences cannot be disentangled from internalised oppression that informs and co-constitutes their expression. Following, Bardzell et al. report their menopausal participants express feelings of "inhabiting a body that is not her [sic] own, or inhabiting a body that is possessed by some alien force" [21, p11]. The authors challenge readers to consider what roles social partners play in the construction of menopausal symptoms; however, they do not appear to take the opportunity to deliver a critical intervention to the participants themselves, with the consequence of menopause remaining a dis-integrated concept for their bodies.

To reiterate, the participant testimony presented in these papers are valid and real experiences that are valuable representations of embodied knowledge. Our use of them here is not meant to invalidate the experiences of participants, but to show that these experiences do not exist in a vacuum absent of cultural context. These experiences are not possible without larger systems of oppression, and these systems need to be acknowledged to effectively deploy participant voice as a means of challenging those systems, rather than inadvertently reifying them.

As HCI researchers, we imagine a new commitment to collectively hold ourselves accountable to the stigmatic constructs that shape our perceptions. In Bardzell and Bardzell's conceptualization of Feminist HCI, they call for HCI researchers to engage with Feminist Theory, empathize with their participants, and involve participants in a mutual co-construction of research aims and goals [23]. To that end, we feel a Feminist HCI must also explicitly reflect on and resist the ways that the narrative products of research artifacts might entangle with and naturalize systems of oppression.

In HCI, the menstruating and menopausal body is denaturalized as always already ill and in need of care and maintenance. In this way, the menstruating body is disabled because it contains a uterus, one that does not bleed on predictable capitalist schedules and cannot be reliably and conveniently classified as fertile or infertile. The menopausal body is disabled because this

unpredictable organ is now “malfunctioning” with age. Some work within our corpus acknowledges this as inherently problematic. Homewood notes [94], that the motivations behind women’s health projects in HCI may inadvertently uphold the “androcentric” othering view of the feminised body. The menopausal body is framed as a dysfunctional menstrual body, the menstrual body as a deviant non-menstruating body, both as conditions of inherent madness, and madness as an undesirable state of being.

Though the stigma of disability is invoked in these discursive binaries between health and illness, predictability and irrationality, youth and age and fitness and weakness, the reality of disabled menstruating bodies is absent. What are the specific needs of those with endometriosis, chronic migraine, chronic fatigue or multiple sclerosis? These are just a few of the chronic conditions that many patients struggle to get diagnosed [83], often enduring medical gaslighting and dismissal [40]. HCI is uniquely poised to provide people with the concrete data they need to advocate for themselves and subvert the toxic pattern of gendered and raced dismissal endemic in so many health-care systems.

Despite this opportunity, engagement with disabled people’s routine health in HCI is rare. Søndergaard and Hansen acknowledge that disabled people who use personal care assistants (PCAs or PAs) have “extensive embodied knowledge on social conflicts with human PAs and potential conflicts with digital PAs” [163]. The disabled workshop participants were asked questions about the nature of their PA relationships and asked to speculate on possible relationships with digital personal assistants (DPA). The authors intend to integrate this disabled embodied knowledge in speculative futures of DPAs that attend to tensions that are otherwise rendered invisible by the systematic sequestration of disabled people.

Unfortunately, by eliminating the disability context from the speculative designs, these tensions of consent, of connection and of care are removed from the historical context of care work—itsself a tumultuous space of complicated gendered, raced, classed and colonial dynamics [63, Chap. 6]. These speculative futures do not attend to the particulars of disabled use contexts, nor the complexities of political relationality between disabled people and PAs [104], and thus further render their disabled informants invisible. The disabled participants have their embodied knowledge extracted for the benefit of a group they are systematically excluded from. Their lived experiences with personal assistance and using assistive technology is leveraged to make a speculative future more convenient for and mainly relevant to abled people. While this is likely an oversight of the authors, we offer this critique to throw into relief the potential futures that not only include disabled people but consider them as active stakeholders in issues related to gender and health.

The erasure of disability in menstrual and reproductive health technologies is especially concerning given the way historical atrocities like Ashley X [104, 112] and Buck v. Bell [1] in the United States of America. Through such cases, surgically induced permanent childhood and medical sterilisation were given cultural purchase to restrict the health and reproductive care access of disabled people. Such infantilization is also reflected in the systemic ongoing policing of disabled people’s sexualities (for a UK perspective, see [120]) and a steadily maintained practice of involuntary sterilisations of disabled women, for example in Germany [197]. HCI in general needs to examine the field’s arbitrary relegation of disabled people to the realm of assistive technology and accessibility. When designing for the “general population”, works should acknowledge that disabled people are an inseparable part of the whole.

Few researchers are exploring the space of HCI at the intersection of disability and gender, and none of the 17 papers in the corpus explore disability in the context of HCI for menstrual health. However, it is useful to explore interactive technologies for disability and gender, because the findings from this small body of work have implications for HCI for menstruating disabled people. Hence, we turn briefly outside our corpus to discuss examples at the intersection of gender and

disability to acknowledge existing work that, however, does not identify itself with the terminology of “women’s health”.

In urban Rwanda and Malawi, mobile technologies enable social integration and navigation of structural access barriers for disabled people, although this effect is substantially diminished for disabled women [143]. This effect of gender on the efficacy of assistive technology is corroborated in a study of voice forums in rural India and Pakistan. Women experienced disproportionate harassment that inhibited their ability to use the voice forums for the formation of affirming communities [182]. Social systems, such as patriarchy, misogyny and sexism, make the analysis of gender and disability essential for effective and equitable design of assistive technologies. This work offers an intersectional perspective on how gender and disability create specific oppressive structures to navigate.

Other authors explore the aesthetic desires of deaf women in a collaborative co-design project for developing hearing devices that take the form of jewellery and fashion accessories [191]. Aesthetic design of assistive technology may improve adoption and facilitate use [147], and aesthetic desires are likely to be influenced by intersections between gender, race, ethnicity and other aspects of identity. Such work argues for experience design for everyone beyond functionality and to account for gendered preferences in this context.

Work by Homewood [94], or (outside our corpus) Fox et al. [70] provide examples of appreciation of bodily variance without adhering to a deficit-oriented summoning of disability narratives, but also address qualitative gendered dimensions of interaction design for disabled people. While the latter examples did not operate strictly within a notion of health research, they illustrate potentials research into gendered aspects of marginalised health could further investigate.

#### 4.4 Discursive Silences in Women’s Health

In the context of women’s health, we have seen (see “A Perspective on the Women’s Health Movement”, above) how sexuality, class, race and cultural and/or geographic assumptions have underpinned both the exclusions of the women’s health movement, and how this history is told in the first place. Correspondingly, we worked to ensure that our analysis of how “women’s health” is framed within HCI works subscribing to the concept was attentive to issues in these spaces. We did so with some reflection, care and caution; although several of the authors grew up in poverty and many of us are sexual minorities, we are all white, and overwhelmingly from Western European and North American contexts. Our collective ability to critically examine questions of space, race and culture is shaped and constrained by this general background.

Recognising that, what struck us was that there was mostly *silence*. It is vital to avoid mistaking this lack of attention for genuine universalism; instead, whatever the intention, it is likely to result in racial, cultural and geographic assumptions weaving their way into research and its interpretation [110]. As Clare notes, it is the straight body, the White body, the Western body, that does not have to justify itself; that does not need to explicitly note its existence [43].

How womanhood and health are understood, what technologies are available, and what designs are appropriate; these are longstanding concerns in both women’s health and critical and reflective work in HCI [22, 96] and so it would be expected to see them intersect in HCI work that focuses on women’s health. Instead we found little to no discussion of this, with the exception of Prabhakar et al.’s “MatHealthXB”, a workshop proposal specifically centred on designing “across borders for global maternal health”, which (understandably, given that framing) considered differences in medical infrastructure and practice in different cultural contexts, arguing for work to “generate...culturally appropriate solutions” [146].



In contrast, the paper on “Communicating Uncertainty”, while collecting data only in German, neither listed this as a limitation nor treated it as a reason to contextualise recommendations of app-based “visual representations for uncertainty...goal-based interpretation aids and uncertainty explanations on the spot”. The contextual differences in app availability (and the nature of explainability and interpretation) do not make an appearance [158]. The “Labella” projects explicitly note participants were drawn from “as great a variety of backgrounds as possible”, but participants were still (implicitly) uniformly resident within the United Kingdom.<sup>8</sup> We are not suggesting that researchers should be expected to recruit from every nation and cultural context on earth, but to understand nationality and cultural differences as necessary axes to reflect on as limitations. Otherwise, we might risk to accidentally buy into top-down, neoliberal approaches to development, which often appear within the neocolonial discourses of normative information and communication technologies for development [172], while the treatment of tradition as a negative thing ignores the many cultural contexts in which traditional approaches to women’s health are vital and often strongly validated as worthwhile [110, 155].

Other works do note sampling limitations, including “Facebook for Support Versus Facebook for Research” and “Examining Menstrual Tracking” [12, 61], but it is noteworthy that only one [146] of the 17 papers in the corpus actively centred non-western contexts. All other studies focused on the United States, the United Kingdom or Continental Europe with one also addressing Japanese contexts. In one sense, this is a limitation of the platforms that are being drawn from—but it is also a limitation of our *work*, if platform limitations are not articulated as a reason to explore other methodological approaches, integrate postcolonial perspectives on HCI [97], and/or avoid envisioning futures for “women worldwide” [19].

Assumptions and defaults can also be seen in how works that mention nationhood or culture frequently tied it to the boundaries of internationally-recognised states; as a result, there is no work (yet) on the subject of indigeneity and health.<sup>9</sup> Discussions of limitations in sampling are often purely state-based, effectively ignoring the role that settler colonialism plays in access to health care and its suitability—a role which has been extensively studied, particularly in the United States and Canada [144]. Indigenous people have produced their own “Indigenist” models of women’s health and its study [186, 190], and their own knowledge of health factors [185]. The epistemologies and existences of indigenous peoples provide an area open for research interested in destabilising the unmarked norms of the white cis-male abled body.

There are many works in HCI investigating gendered, health-implicated phenomena across cultural boundaries and outside a normative western context—and it is not a problem with any of these papers that they do *not*. No work has universal scope. But it is a problem that the majority of papers in our corpus takes near-identical frames of reference and research. We urge researchers to build on the work of the MatHealthXB paper and other positive examples outside of our corpus (e.g., [34, 106, 178])—albeit all of them working from an assumption of “woman” being equal to “cis-woman”), collaborating with researchers studying colonialism and/or the experiences of women and their health in non-western contexts [6], so that we may (collectively) better articulate an inclusive and plural agenda for this work.

Papers were even more silent on issues of race and class. Some of this is undoubtedly for some of the same reasons concern has been raised about considerations of race and class in HCI as a whole [59, 84]. “Investigating Support Seeking” notes international limitations around the US-based nature of most of the field site’s users [82], as does “Announcing Pregnancy Loss” [14], while

<sup>8</sup>We reflect on the difficulty for a single paper to achieve this and illustrate our own limitations in Section 5 of the article.

<sup>9</sup>We place questions of indigenous health within the section on nationality out of our recognition of the sovereign status of indigenous peoples.

“Facebook for Support” notes that Facebook has widespread use in the Western world but not elsewhere [12]. In each case, however, there is an elision of classed and raced differences within the USA (or Western world). This is of great concern given that both class and race play a tremendous role in mediating the probability a person has reliable access to online spaces, and mediates behaviour and experience within those spaces [159, 194]. For example, race is a significant factor in one’s experience in online harassment, which research investigating harassment has been critiqued for failing to consider [124] and an intersectional approach to the health and well-being of marginalised populations within HCI should consider [50, 157]. Analyses of online support structures that fail to consider race and class, or advocacy of the use of online spaces for support around women’s health, risk replicating these issues if silent on them. Race and class are highly relevant dimension to any research centred on health as they play a tremendous role in causing drastic treatment delays, in everything from cancer to post-childbirth support, and reductions in treatment quality and availability [16, 77, 100, 181].

Lesbian and bisexual women are similarly erased within the literature. One paper (“Announcing Pregnancy Loss”) noted a lesbian participant [14], while Bardzell et al.’s “(Re-)Framing Menopause Experiences” assumes a “male partner” and imagines an application wherein “men [do] makeup and nail polish for their wives” [21]. Most papers, however, despite the overwhelming focus on “reproductive” health, were simply silent. This is of concern given the inequalities present within the area of health this work looks at (gynaecology) which is frequently highly heteronormative—it assumes heterosexuality [65, 130]. This results in substandard care, discrimination and treatment that is “not fit for purpose” [136]. Seeing as over a third of women in one sexual health survey identified as members of sexual minorities [64], this discarding of homosexual and queer desires seems particularly cynical [105].

All of this is not to say there are not positive signs—many of the works in our corpus do caution the limitation of their participant pools or frames of reference, and are doing valuable work for undersupported groups. All of the work is valuable—but that work collectively follows such consistent themes risks artificially curtailing our sense of who and what we should be supporting and scaffolding. Hence, our analysis also offers this critique early on so that research on gendered and marginalised health interested in destabilising a normative status quo can diversify and become equitably accountable early on.

## 5 SPECULATING ON FEMINIST HEALTH TECHNOLOGIES

Feminist studies of bodies, disabilities and assistive technologies predominantly concern themselves with the critique and analysis of a status quo, whereas the design strand of HCI aims at future possibilities. In a series of speculative designs, we explore how our previous analysis can be made productive for future-oriented technologies around the health of marginalised bodies in HCI.

### 5.1 Method: On Sketching Speculative Designs

Speculative design approaches can illustrate a range of pathways for potential design spaces of how society might develop and a reflection on the direction technological advancement is currently heading [56]. From a phenomenological perspective, speculating on feminist utopias concerning topics of marginalised gendered health through design enables us to explore the resistance of designs and objects and encounter points of friction often outside of purely analytical inquiry [127].

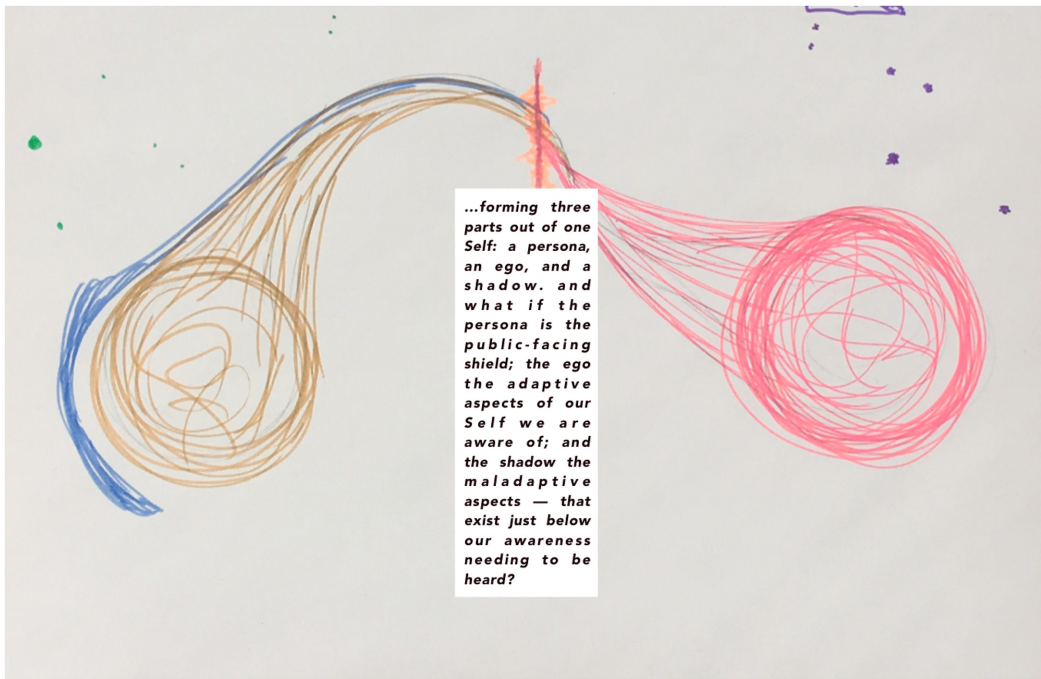
Within HCI, the approach of sketching on designs without the aim to necessarily follow through on them as an epistemological technique has gained some traction in recent years. For example, Lawson et al. [116] used speculative design to explore the ramifications of quantified pets, DiSalvo et al. [53] speculated on the notion of digital civics and Kozubaev [113] embedded their speculative design in a fictive frame set within a near future in which privacy is negotiated very differently.

The work on menopause resulting in “design frames” [21], that is also part of our corpus, can be seen as part of this tradition even though it draws more on the sketching than on the speculative side. In that regard, we also embed our work in a growing corpus within HCI that argues for visual methods and sketching as modes of knowledge generation [119, 153, 175, 176].



Our own approach on sketching speculative designs is largely inspired by the work of Wyche [193]. More rigorously, we use ecological validity by drawing on our previous critique to establish narratives describing fictional but realistic contexts that are relevant to the integrity and well-being of marginalised bodies. We then envision our designs as part of a verisimilitude—a world that is not actually present, but believable. Both of these strands feeding into our approach draw from the methodological work of Auger [17]. Our speculations allow readers to follow our thought process aiming at actualising the critique by designing alternatives that disrupt the status quo. They present a way of engaging with theory as a form of “staying with the trouble” [86], where through stepping through design deliberations, we learn how to actualise and strengthen our critique. In an ideal world, of course, this design would not be *speculative* at all; as we discussed in our analysis of how “women’s health” is framed, the treatment of vulnerable populations’ needs as a site solely for speculation is discomfoting. But our core argument, again, is that this discomfort stems in part from the imbalance in whose needs are designed-for versus speculated, and a failure to attend to the material impact of an absence of design. Our hope is that the analysis, and this speculative work, will point to ways to address both issues.

We actively refocus on populations who have been marginalised in health research, particularly as this pertains gendered health concerns (see critique above in Sections 4.1 and 4.2). Our aim was further to disentangle, at least to some extent, tensions around internalised oppression and how this shapes actions without ignoring an individual’s agency (see Section 4.3). In our designs, we use visual language and nonverbal communication modes to be flexible concerning different languages used and consider different implications stemming from multiple marginalisations an individual might experience (see Section 4.4).



Specifically, the two speculations were individually designed by Peil (Shadow Zine) and Spiel (Compass). Both designers started by collecting a range of ideas and quickly iterated over a few. In doing so, we continuously reflected on ecological validity, desirable discomfort, the narrative, roots in familiarity, counterfactuals and alternative stories as well as the power of literal metaphors [17]. Peil took Jung’s theories of the Self [103] as a starting point to develop a zine providing an opportunity to talk about mental health in self-defined terms. In stepping through different points of critique, Peil develops a set of questions for guided reflection and expression. Spiel’s process took the critique as a starting point and decidedly stepped outside a classical health scenario to be able to address issues beyond categorisations of physique or social role. Spiel’s goal in iterating over context, narrative and technological object lay in implementing with the critique in mind while allowing for acknowledgement of limitations of design in a productive manner.

## 5.2 Shadow Zine

To expand our findings towards a theoretical speculation, we now speculate on how we might design a text that embeds three elements our data suggests may be absent in modern health-care systems for feminized identities: (1) reimagined possibilities, (2) flexible frameworks for empowerment and (3) community support. Specifically, this text will be used to support participants through a praxis for liberating their minds [75] as a matter of public health. Theoretically, the most direct route for liberating the mind is reconnecting to the body i.e., healing the Cartesian split that has been passed on for centuries in “Western” cultures. This reconnection is facilitated by dialoguing with the body through reflective dance, introduced in this text in the form of movement journals. Importantly, this text seeks to explore how we might empower individuals to rethink and pursue their own mental well-being, perhaps democratizing mental health.

**5.2.1 Recognising a Status Quo.** The need for such democratization is reflected in trauma research and transformative learning theory who together clearly outline the following pattern:



trauma experienced without support yields a negative outcome [107, 132], sometimes as extreme as post-traumatic stress disorder (PTSD). Furthermore, PTSD feeds a positive feedback loop of trauma without treatment, i.e., traumatized people traumatize people, often times without being aware of it consciously. Unsurprisingly, many violent offenders have experienced trauma. Because of this pattern, many trauma experts view PTSD as a public health epidemic [180]. When feminized populations have been traumatized enough, how might we better understand this pattern?



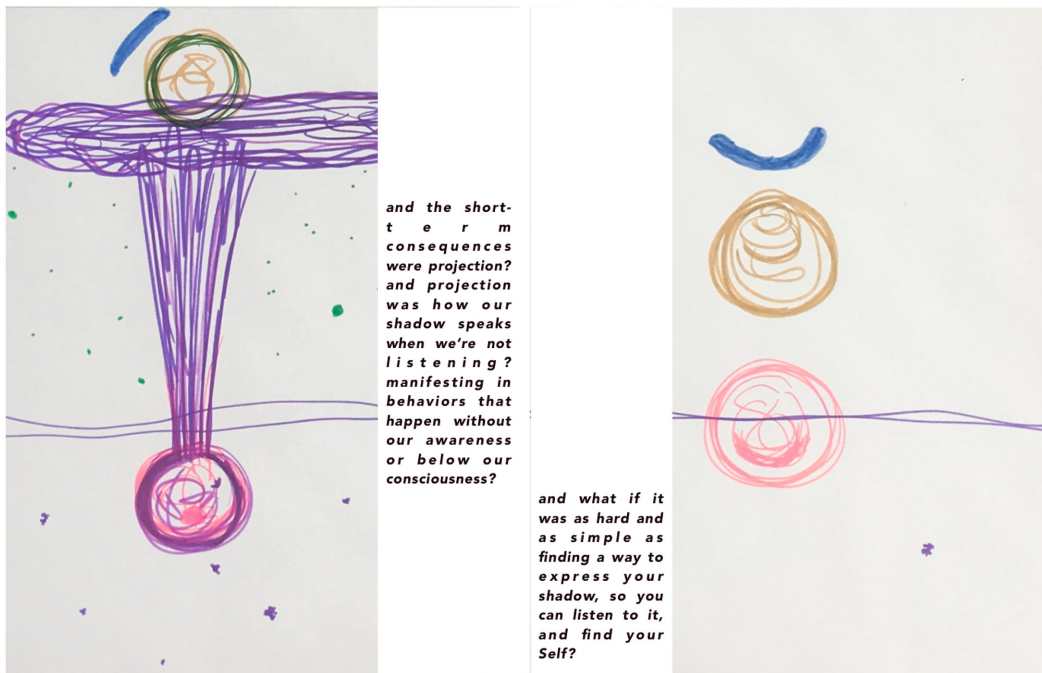
Problematically, current methods in psychology render PTSD as difficult to “diagnose” using the Diagnostic and Statistical Manual of Mental Disorders (DSM) and International Statistical Classification of Diseases and Related Health Problems. This is because PTSD mimics other conditions, such as bi-polar disorder, multiple personality disorder and depression; the medication for addressing any of which can do more damage to participants if the actual source of their challenges is PTSD [180]. A common symptom of those suffering from PTSD is disassociation, wherein the individual disassociates with their body, and even a true sense of who they are. Taken together, this creates even more urgency for feminized identities to know themselves, so that they may become advocates for their own health until their health practitioners are willing and able to serve as accomplices,<sup>10</sup> perhaps aided in this expertise through dialoguing with their shadows, including their own bodies.

**5.2.2 Zine Specifics.** We envision this text as taking the form of a Zine, here referred to as “the Shadow Zine”. It serves as a theoretical narrative [81] of our design practice, as a sensitising concept for ourselves, but also as a text for establishing a community of care to join us in rethinking mental health. The zine is based in Carl Jung’s theories of the Self [103]. Rather than rendering a

<sup>10</sup>This also represents our attempt at reconciling the tension between understanding health as a larger socio-technical issue that needs to be addressed systematically and the currently lived reality in which individuals need to be responsible for themselves to survive.



self on one side of a polar spectrum of good or evil, the counter-discourse that could rise from this zine reframes humans as multi-faceted and in permanent flux inverting dominant notions of what a self is. In thinking through the implications of such a design, we first turn to thinking through inclusion and accessibility. As a choice of medium, zines are visual and concise, serving to support comprehension for a spectrum of learning styles. They can be created, replicated and distributed rather inexpensively compared to other forms of similarly concrete communication. Furthermore, the visuals in this zine are intentionally simplistic to lend themselves well to translation into tactile imagery to complement expected Braille translations. In thinking through the applied practices, such as movement journals that make space for our shadows to speak with us, we assume participants will modify any frameworks presented to their own needs and that this modification will be an asset rather than a threat.



The envisioned audience for this zine is systemically disadvantaged groups [4], including those who have been historically feminized. Feminization is used here to refer to the process by which a body is ascribed as feminine by an external entity, tying it to certain expectations and systematic devaluation. Feminization extends beyond gender, e.g., feminization has historically been used to subjugate people of color and people living with disabilities. Devalued identities are particularly susceptible to trauma by way of living their everyday lives in a system that overemphasizes minds over bodies, masculinity over femininity, whiteness over any other race, able-bodies over bodies rendered as socially disabled [141], and the like.

Jung thought of humans as being born as their full self. Their caregivers, peers and experiences then shape them. This shaping happens through interaction, wherein the individual is taught which characteristics of their self are adaptive to their environment and which are not. The adaptive characteristics form their “ego” or the personality the individual is consciously aware of. Their “maladaptive” characteristics are then molded into the shadow, which is submerged just below their conscious awareness. Importantly, these shadow characteristics are not to be classified as bad or evil, but rather do not fit (in the Darwinian sense) their environment. Jung theorized that

this process of socialization was trauma in itself and that this split between the ego and shadow was the germ of “(psycho)pathology” that lives in all of us. [103]. We might also think of the split Self as a oppressed mind.

## movement journal praxis

**1. choose a song of resonance (emotional)**

**tip:** maybe the song you choose verbalizes something you cannot or helps you move through what you're feeling.

**2. record yourself moving to this song (kinesthetic)**

**tip:** try closing your eyes and listening to one wave of the song e.g., an instrument or the vocals and moving with it

**3. edit this recording down to 1-3 clips to form a vignette, i.e., a significant narrative to you (expressive)**

**tip:** empower yourself to form your own narrative

**4. write an extended reflective caption (reflective)**

**tip:** you might focus on something you knew, but now think differently about or who you are becoming

**5. post this vignette to a social media platform (exhibition)**

**tip:** this can help you reflect on another level, e.g., through the looking glass/with a mirror/anticipating another

Importantly, the shadow is believed to be the source of undeveloped talents and creativities. The warning here is that if humans do not learn to dialogue with their shadow, their conscious personality will lose affinity with the centre of their true self more and more overtime. The threat here is becoming a false self or someone the DSM might consider a “psychopath”. We saw this

Jungian story arc as an engaging narrative for the zine that might attract people to think with, and aid them in concretizing rethinking their own health through questioning wholeness, authenticity, and dialogue. These dialogues are a form of what Jung called shadow work, which is an individualist version of shadow play.

Historically, the shadow framework has been used by Jungian authors to reflect on the valuations mentioned above with archetypes as objects to think with or to provoke emotion and thought [179]. That is, the archetype of cisgender men have been framed as the ego with cisgender women being framed as their shadow, rendering trans women and non-binary people invisible. Other examples include the body as the shadow of the mind; illness as the shadow of health; the disabled body as the shadow of the able body; LGBTQIA\* folks as the shadow of heterosexuals, and so on. However, future iterations of this zine, which is in itself an object to think with, seek to reframe Jung's notions of shadow work by integrating intersectional [45] and spectrum thinking [160]. The call of this reframed shadow work is for participants to find their own balance within the intersection of these spectrum constructs, rather than finding imbalance within the constructs of established wisdoms or archetypes within society's "center". According to Jung, such balance can then support well-being, as well as authentic, creative lives and the ability to hold pluralistic ideas compassionately. All of which are foundational elements for social equity.

Theoretically, acknowledging the shadow requires acknowledging the pain the split brought on initially in its coerce mediation of our belonging. This motivates individuals to deny it, even in the face of the destruction of themselves and others. Because of this relationship between a lack of awareness of the shadow and potential violence, we speculate a shadow framework stemming from the knowledges encapsulated in the Shadow Zine could serve well as a sensitising concept [31] for health care—perhaps particularly when it comes to integrating de-essentialised health care for feminized identities. That is, what the Shadow Zine provides us with is a tool for reflecting on health and conversing about challenging existing norms influencing designs.

### 5.3 Compass

To expand into the direction of technological design, we now speculate on a tool that embodies the notion of community care.<sup>11</sup> One that has no single person as a point of contact interaction, but rather one that functions as a communicative device from one person to another, to let someone know that they are not alone in a difficult situation, and that there are ways out—a compass.



**5.3.1 Recognising a Status Quo.** Domestic violence is a complex domain in which multiple marginalisations are entangled within complex dynamics. Cultural [44] and class [15] issues tie into its occurrence and complicate this space. While there is a predominant notion of a binary gendered space, authors more and more consider an intersectional lens [148]. This becomes particularly relevant seeing as LGBTQIA\* people experience increased barriers concerning their abilities to gain access to services [37] and disabled people are exposed to higher rates of abuse in general [48].

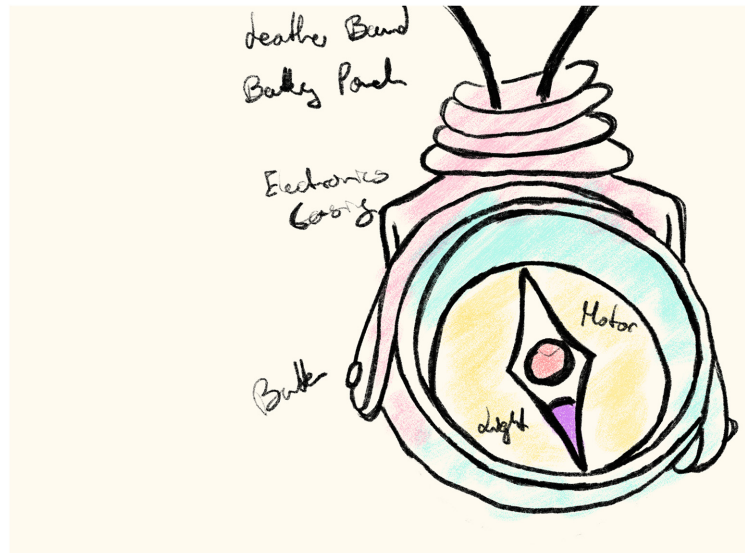
<sup>11</sup>In that spirit, we warn readers that the next pages may contain triggering content on domestic violence. We want you to be safe and be able to make informed decisions around this text.

Concerning domestic violence, technologies often play a shameful role in enabling abuse [73, 74, 192]. What enables social connectedness and community in the most ideal cases, can quickly turn around and be a tool for control and isolation. However, HCI's response to these difficult situations seems to be to identify different privacy strategies [128] of survivors and implicitly tying the responsibility to keep perpetrators at bay to them by requiring them to install specialised apps [52] or require them to monitor the whereabouts of their abusers [101]—a notion which is particularly toxic as it expects survivors to be attentative and alert, constantly concerned about their abuser's location, essentially maintaining the toxic power dynamic into the spaces that were sought as refuge. Other works aim at developing tools for survivors to process their life after the fact [44] or the technological ecology of domestic violence service providers [27]. It is also relevant to note how these works operate mainly in the post-hoc of domestic violence without necessarily aiming to design for the messy transitional context in which survivors move out of abusive spaces.

Framing domestic violence as a concern for marginalised health acknowledges the very corporal and mental damage abusive situations cause not only to the main target, but also to bystanders and observers that are similarly dependant on the abuser (e.g., children [58]). We came to this context by brainstorming on different gendered health issues that are often marginalised, without a clear solution and that operate in highly complex places. These explorations included considerations around systematic mental health negotiations, political activism (a long-standing tradition within the “Women’s Health” movements) and community support. Our final technological sketch is intended to support people in disengaging from abusive power dynamics. The compass is meant to support people in recognising their responsibility for others (to encourage community care), initiate and guide it, but also provide information to the survivor. It aims at offering tools for agency instead of furthering a notion of “saving” someone else (in the spirit of [78]). The design sketch itself comprises a tool-to-think with, an exploration of how thinking and design can take the concept of attending to marginalised health without claiming perfection or completeness. It is deliberately open to allow for further critique and reflection concerning marginalised health in general and domestic violence specifically.

### 5.3.2 Compass

*Specifics.* The compass is a token that one person gives to another. It can function as jewellery, but it can also guide someone to a safe location should they decide to leave. For this to work, the compass will need to be able to store a location and know its own location to be able to have its guiding function. Given that the arrow can only point in one direction at a time (dependant on the mode of transport), changes in direction need to be signalled personally and unobtrusively; we envision here soft vibrations. The energy management of the compass needs to be efficient to ensure a long battery life time



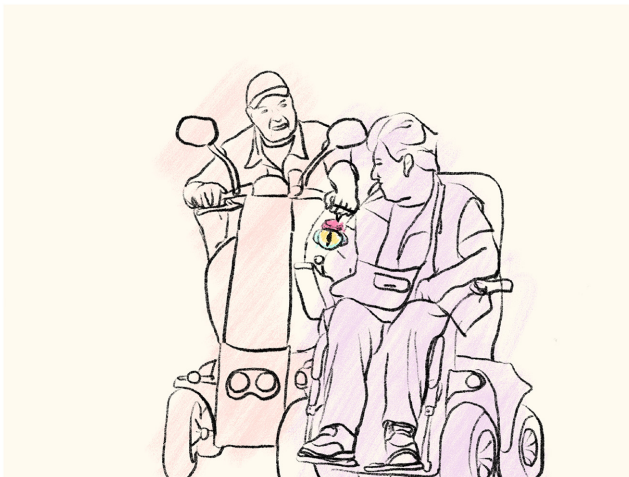


and allow the object to be readily available to function within the intended context. Charging should then be a quick and a simple process. The object needs to allow for plausible deniability regarding its alternative function as jewellery. The aesthetics also need to work in a broad range of contexts across genders, cultures or even placements. Most of all, it needs to be utterly useless for intentions of control or abuse.

Some components of the compass are illustrated in the Figure on this page; they can be distinguished between technological and aesthetic components. Technologically, the compass will require a range of sensors, (e.g., Global Positioning System, orientation and velocity), a battery and charging spot for it, a vibration motor and an actual motor for the needle, buttons that start the navigation, an internal clock that allows for resetting, if there has been no change in location within the last 5 minutes (also to counteract any potential abuse) as well as some background lighting for dark environments. Aesthetically, the casing consists of light-weight, non-corrosive but sturdy material and a (faux) leather band that allows the compass to be worn as a necklace or wristband but also makes it possible to attach it to, for example, a keyring or a bag.

Scarcity of data is core to the design of the compass. It is only able to store one target location at a time. That one can only be overridden, once the target location has been visited at least once. It cannot share its target location with any other device, the only thing it communicates to the outside is whether a new location can currently be set or not. The direction for the next step is only shown after two buttons have been pressed simultaneously, for 5 minutes. If the object has not been moved substantially towards that direction for 5 minutes. Otherwise the compass slowly spins and points down again. That way, information is given dependant on the current situation and becomes virtually meaningless to a potential abuser.

**5.3.3 Transition in Use.** The compass is not intended for a static single person or group of people, but rather is a transitional object per default. Instead of supporting progression within a status quo, it specifically targets a transitional process which might come with variable length.



The starting point for encountering the compass lies outside the core context of domestic violence. We envision that someone in the extended support network of the target recognises (or fears) that domestic violence is a current issue. Due to the isolating power dynamics of domestic violence, they cannot directly support the target, though. The friend would then, as a matter of caring for others within a community, either research appropriate safe houses (e.g., low-access and trans-friendly), which might also be their own place. It is necessary that this is

not an automated task as the specifics of needs cannot technologically anticipated and the compass should not assume that it could. They then set up the compass and store the location of the safe house. The compass can then be handed over using coded language, for example “Press both buttons if you need a friend”. Now, this is necessarily a bad example given that coded language is highly contextual to a specific situation and needs to be carefully prepared. After the handover, the compass initially becomes dormant, used potentially as an accessory or just stored somewhere.



**5.3.4 Individual Redundancy.** With the handover, the compass communicates a notion of care and support; it makes an offer. Whether that offer is appropriate and if so, taken up upon, is decided by the target. They decide what happens next and when. However, their support network took on the effort of identifying a suitable safe space outside of the toxic environment. Hence, what outsiders offer here is to take up some of the effort it takes to identify a potential place to go to and to do this with care. In any case, the compass is entirely useless in its technological function outside of this context. Besides that, though, it also functions as a token to indicate said support and care, and it has the potential to then become a token indicating (hopefully) positive change.



Of course, this is somewhat complicated. First of all, the compass might be handed over in circumstances where the implication of domestic violence is entirely inappropriate. The concept requires for implicit communication to convey fairly complex and concrete information. It further requires the target to be able to trust the person who hands the compass over generally and also specifically in identifying a suitable safe place. After all, they would blindly follow directions from an otherwise dormant object. As a design sketch, the compass illustrates how designers and researchers could critically engage with (gendered) marginalised health issues.

**5.3.5 Health Beyond the Individual—Reflecting on the Compass.** With this speculative design sketch we tried to explore what it would mean to design for marginalised health more holistically; to take an issue, which has not only been largely addressed with an implicit binary concept of gender, but also one that is put outside the notion of health even though domestic violence has very pronounced ramifications for corporal and mental health. We further aimed at a design that does not individualise the responsibility of addressing this issue, but aims at a communal responsibility of care for self and each other.

The device conceptually addresses more than one person engaging with it and expects different people to take on different roles and communicate them. Hence, the meaning the device has for different people in different contexts also changes. Fundamentally, though, the compass is designed for obsolescence. What it supports is a transition after which it does not define

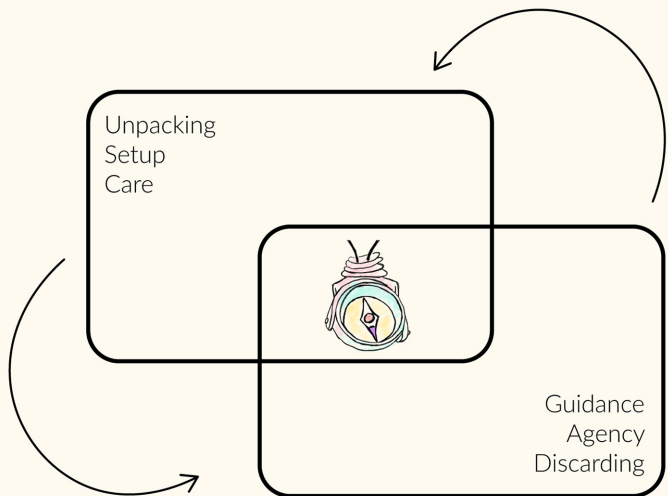


Table 2. Critical Considerations Around Marginalised Health

Dimension	Counter Strategy	Reference
Biological Essentialism	Engaging with gender flexibly without assuming specific bodies	Ahmed [3]
Disability Erasure	Strategically as well as casually involving different disabled perspectives	Bennett and Rosner [29]
Western Norms	Positioning work critically and prioritising non-western standpoints	Irani et al. [97]
Singular Perspectives	Understanding marginalisations as multi-faceted and intersectional	Schlesinger et al. [157]
Individualising Health	Acknowledging and actively engaging with the social circumstances affecting corporal and mental health	Crawford [49]

its own meaning. Potentially, survivors could then support other targets by recycling the use of the compass and create an ever growing support network among those sharing relatable experiences—a rather speculative consideration.

In that regard, we need to specify what we understand as speculation. After all, the design above could potentially be feasible now, if developed within the necessary frame and associated infrastructure [32], for example in collaboration with survivor organisations. However, the speculative part in our work lies not within the context or the solution itself; instead, we speculated on how critical design addressing the inherently restricting concept of “Women’s Health” as it is currently prevalent in HCI might look like. It is an exercise in thinking through an identified health issue more holistically and with a strong emphasis on designing for agency in marginalisation.

## 6 DISCUSSION

Existing work on “Women’s Health” has provided a vitally important framework for engaging with marginalised perspectives in discussing who matters in the design of technologies supporting corporeal and mental well-being. Without this scholarship, our cautionary analysis *itself* would lack scaffolding and context. Nevertheless, as our analysis shows, HCI needs to go further than it has if we as a community wish to avoid simply repeating the discursive debates and exclusions of the (historic) women’s health movement. We would also be lacking if we did not recognise existing critical work within HCI that has worked to surface many of the individual strands of our concerns—work that we surface in Table 2, and invite readers to engage with in addition to our work. We would further be remiss if—having spent many pages urging critical reflection—we were not similarly reflective on our own work, an activity we engage in below after the discussion of counter-tactics.

### 6.1 Counter-Tactics in Designing for (Gendered) Health

These works, in conjunction with our own, suggest a range of potential *counter-tactics* to the issues we have raised. Many of them centre on the need to design *without making universal assumptions about context*. This requires humility in design and a trust in non-technical social communities. It also requires rethinking the role of technology in health more generally—away from trying to define what it means to be “healthy” towards acknowledging and amplifying agency around the integrity of bodyminds [167].

Similar to Ahmed [3], we suggest that the multitudes of lived experiences around gender identities need to be actively acknowledged. This means that technology design on marginalised health

does not assume a specific body, gender or identity to be congruent with another. Instead, designers engage with flexible and potentially fluid notions of gender in individuals, but especially across groups. The compass tries to accomplish this by an unassuming aesthetic and flexibility of placement on bodies or things.

Traditionally, HCI has drawn on health-related knowledges from subject matter experts<sup>12</sup> and empathy studies, but we recognize the reductionism documented here [29], the ways in which these approaches do not work to redistribute power, and the ways in which knowledges gained from such practices are highly mediated by expectations of an ideal body in terms of biology, ability, color, shape, and the like, silencing the stories we could be rethinking with [28]. The lived experiences of disabled people are so fundamentally individually situated that designers trying to incorporate these perspectives are profoundly limited if they do not actively involve disabled perspectives [29]. In that regard, Mankoff et al. [125] echo the often made demand within disability culture to include disabled people in research about them. However, to acknowledge the different and shared experiences of disabled people when it comes to health related topics,<sup>13</sup> requires designers to strategically (e.g., through participatory approaches) as well as casually include disabled perspectives. What we identify as a casual inclusion is, for example, how we chose to illustrate parts of the interaction around the compass with wheelchair users. Critically speaking, though, we bought into a normative picture of disabilities being represented by wheelchair users.

Avoiding the normativizing of Western contexts will not be possible within an academic structure as it currently presents itself, with western institutions receiving the majority of funding and defining the standards of scientific discourse. As individual researchers will not singularly solve this systemic issue, Irani et al. [97] offers some guidance on how to position one's work on a global scale, particularly through active engagement, explicit articulation of contexts and careful translations. This work has similarly been conducted by researchers based in North America and Europe and our design sketch fails, on a methodological level, to address larger global contexts.

In focusing exclusively on binary notions of gender, the field of "Woman's Health" risks normativizing who counts as a woman. A risk that can be addressed by including multi-faceted marginalisations particularly as they intersect [157]. By attuning research and design to marginalised perspectives on health, HCI could not only be more encompassing about the identity categories that "matter", but also move away from an incidental focus on reproduction. The compass has such considerations as a starting point. However, we acknowledge that we emphasised some aspects more than others and by not addressing race specifically operate on a default of white people as actors in this space. In that regard, our speculation illustrates how getting all aspects right in design might not be achievable; nevertheless it should be a goal for which to strive if only to reflexively make choices and negotiations explicit in relation to dominant discursive power structures.

Another aspect contributing to this more holistic understanding of marginalised health lies in acknowledging the inherent social makeup of any individual's health [49]. Instead of positioning the responsibility for (self-)care within individuals, technological design could address communal care and consider social contexts to adequately support a shift away from toxic systems [109]. The compass speculation addresses this by going the first step of engaging with change as something that can be guided by more than one person.

Returning to the starting point of our investigations, the notion of "Women's Health" and how it explicitly articulates itself within HCI, we encourage readers to look at the transformative potential inherent within: What these works do, is effectively establishing and undermining an implicit

<sup>12</sup>Ironically often those who do not experience marginalisations directly [195].

<sup>13</sup>We are aware that in many cases the boundaries between disability and illness are discursively blurred, particularly when it comes to mental "illness" [134].

norm. Hence, we consequently go with this original critical movement and identify the underlying power structures that privilege certain bodies (and their health) over others. Fundamentally, rethinking (women's) health subsequently means to take this analysis further and to think in notions of marginalisation, harm and power distributions. We tentatively suggest, this could be achieved by designing for obsolescence, embedding designs in positive community structures, actively addressing the intersectional aspects of marginalisations, and radically including the situated knowledge and expertise of marginalised people.

## 6.2 Reflecting on Reimagining

We believe that our analysis and critique has substantial potential to encourage a reimagining of women's health research in HCI, producing a world in which research is undertaken in a more explicitly critical and reflective way, one that takes less for granted and engages more methodically with which perspectives are dominant, and which perspectives are excluded, through how research is framed. In alignment with this, it seems apropos to critically reflect on what *else* this work might do, how it is situated, and how it is limited.

While our analysis is centered on the researchers and designers who wrote works within our corpus, our recommendations and claims are not the sole responsibility of those parties, rather, they are simultaneously the responsibility of the wider HCI community, the power structures in which these authors operate,<sup>14</sup> the schemes of intelligibility and recognition those structures allow and the ways in which all of our work is culturally and politically mediated.

Along these lines, what are the limitations and mediations of *this* paper? As a collective of authors, our standpoints are (as previously discussed) not entirely normative, but also not representative. Our insights into questions of race and geography are highly limited, and should be understood as such. Even in those areas where we do have lived experiences, those are only a small *set* of experiences. We aspired to be far more multiplicitous and intersectional in our analysis, but found ourselves limited by the range of our perspectives and our commitments to avoid speaking for experiences beyond those in which we have lived, along with the "unmarked" nature of race and culture within the corpus we are analysing. Such an unmarkedness signals the naturalization of whiteness, but also of the colonial "West" or the "Global North" of which our experiences hail from. This is a silence of which we should all be concerned, particularly in the context of HCI's wider ecosystem, which predominantly represents white and Western scholarship.

In conversation with our colleagues of color while developing this article, we came to the conclusion to focus on our embodied knowledges gained from our own lived experiences while aspiring to consciously contrast the unmarkedness we found in our corpus through practicing the recommendations we make in this article to consider marginalized health more generally and be explicit about who we were including, why, and where we saw our work as in need of intersectional evolution. Moving forward, we invite our colleagues to help us theorize on responding to this tension responsibly. As Section 6.1 suggests, the framework we present in this article serves to operationalize a reflective methodology in which we were able to begin to develop a praxis for

<sup>14</sup>This includes ourselves. For example, a personal statement: I (Katta) could have challenged the use of the term and its associated essentialist frame in the publication that was part of the corpus [26]. I decided not to do so thinking that the publication was non-archival and I was simply excited to be included in such a networking opportunity. By focusing on the potential professional benefit for myself, I lost view of the larger context in which I contributed to the perpetuated and reiterated harm towards my own communities. In doing the work described in this article, I recognised my complicitness in acting "as expected" within the dominant dynamics of academic status, and it is precisely the reason why I hope our analysis might serve others in similar positions to urge such reflection within the constraints of what is valued and "accepted" as knowledge within academia.

reflecting on our work, identifying ways in which we failed to meet aspects of our framework with our initial exploratory speculations shared in this article. Of course, by identifying these failures, we also identify sensitivities and thus opportunities for future work. Further, there are entirely-absent spots in our conceptions of both health and embodiment. For reasons of time and space, we did not discuss issues of size or age; further, we did not extensively question the basis of “healthism”, the neoliberal notion of what it means to “act healthy” and the value that is given to certain kinds of behaviours as desirable [49].

In future work, we therefore intend to continue to apply and ameliorate our theoretical and speculative analysis to concrete designs beyond the dimensions we have addressed here. For example, some of the authors are currently preparing work that challenges notions where body sizes are correlated with health status—an issue that disproportionately affects cis women and trans people. Other authors are working on intervening within the dearth of literature on how women of color, queer women and gender nonconforming people are disproportionately targeted by gender and sexual harassment, arguing harassment is no less than a matter of public health and collaboratively prototyping programs with a trauma psychotherapist for supporting the well being of these groups and their pursuit of justice. In line with our critique above, we will then aim at a mix of individual and collective technology addressing different levels of systematic and localised entanglement. In addition to this further exploration of the design space, we will aim at a formalisation of processes that allow designers to systematically avoid essentialising the bodies they design for. We additionally invite authors coming from different standpoints and lived experiences to extend our analysis and go forward in implementing more socially just futures together.

On a different and broader note, our inquiry into the notion of “women’s health” is undertaken partly as meta-critique; when taken in conjunction with our own experiences of fitting uneasily within the frame of “Women’s Health”, we recognise that the result might read to others as unexpectedly and perhaps unnecessarily critical. Given this, we want to emphasise that we have undertaken our work from the perspective of people who believe women’s health researchers in HCI are doing valuable and vital work—our critique is because we want it to develop further. Part of the motivation for the speculative design part of this article is precisely to go beyond critique: to provide ideas of how we might, quite literally, re-imagine the context and open up the design space. At the same time, we are convinced of the value of *practice-oriented interventions*—the necessity of not solely speculating or prototyping on design, but constructing and building robust systems. A future direction for this work, and indeed for much of the subfield, is for us to turn our eyes to the material: to ask how we can not only hypothesise or prototype tools, but place them in the world.

Our critique, in other words, should neither be read in opposition to existing work on “Women’s Health”, nor in opposition to its authors: we *all* exist in an imperfect world replete with tensions, tradeoffs, exclusions and limitations. Such an existence is an inevitable consequence of the situatedness of knowledge and bodies—a consequence that applies to the authors of *this* article, just as much as it does the authors of the works we analyse. What we are calling for, then, is not a dismissal of prior work, much of which is of value, or a change in the perceived utility of it. We are simply asking that researchers recognise, and explicitly grapple with, the tensions and exclusions inherent to feminist work in the messy world we live in, and seek to move forward in dialogue rather than denial [79].

## 7 CONCLUSION

Inspired and intrigued by the call for this special issue to reimagine (women’s) health, we took up the challenge to fundamentally question what is meant by *women* and *health* in this rapidly growing area in HCI. Our contribution comes in part from how it is situated within our own charged



experiences around gender, health and technology. While the identification of the default body in HCI as cis male was paramount to establishing a notion of “women’s health”, we argue that the field should rapidly move beyond this specificity and, more fundamentally, attend to and address issues around (*gendered*) *marginalised health*. We illustrated how the current focus inherently excludes trans, disabled and non-western perspectives while simultaneously neglecting intersectional entanglements of multiple marginalisations. Additionally, current work seems to be predominantly concerned with reproductive issues and technologies assuming individual responsibility. Hence, this work takes stock and in addressing the discursive limits of the field identifies opportunities for future work.

To productively contextualise our critical analysis, we then speculated on alternatives to the status quo. With the Shadow Zine, we traced ways to reflect on and communicate our standpoints for sensitising in design activities and with the compass, we explored parts of the design space and the thought processes involved in designing for marginalised health perspectives simultaneously acknowledging the needs for community care and individual agency.

Our contribution lies in addressing *theoretical* frames foundational for the field, providing a *critical* analysis of the work on “Women’s Health” in HCI and illustrating the *designerly* consequences that stem from engaging with our critique. By building on existing work on “Women’s Health” in HCI and critiquing it in solidarity, we aim to encourage the field to “stay with the trouble” [86] in challenging essentialist and normalising tendencies.

## AUTHOR STATEMENT REGARDING PRIOR WORK

This article entirely presents original work that has not been published or submitted elsewhere.

## ACKNOWLEDGMENTS

Getting this article from an idea to a publication took a lot of work—far more than the authors originally expected. We would like to thank those who have helped, collaborated and joined us in various ways. We are indebted to the external reviewers, who sharpened our contribution with their feedback and critical comments, and recognise the editors of this special edition for prompting the conversation this contributes to. Finally, we would like to acknowledge Morgan Scheuerman, Janis Meissner, Sucheta Goshal, Daniela Rosner, Neha Kumar, Gopinaath Kannabiran, Geraldine Fitzpatrick, Sarah Fox and Margret Wander for their support, counsel and critique.

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Received June 2019; revised March 2020; accepted May 2020