

# Using Data to Approach the Unknown: Patients’ and Healthcare Providers’ Data Practices in Fertility Challenges

MAYARA COSTA FIGUEIREDO, University of California, Irvine

H. IRENE SU, University of California, San Diego

YUNAN CHEN, University of California, Irvine

---

Medical practices have always been data oriented: healthcare providers decisions are based on data, both clinically generated and patient reported. With the increased use of patient-generated health data (PGHD), other types of data are entering providers’ practices and influencing patient-provider collaboration. We studied the use of PGHD and its related data practices in the context of fertility, a health concern that is uncertain, complex, and data intensive. We interviewed 14 patients who are facing or have faced challenges to conceive and 5 healthcare providers specialized in infertility. Our findings show that patients and providers use PGHD in different ways but with the common goal of exploring “the unknown” generated by the uncertainties of fertility. Providers use patients’ data in a rational protocol, aiming to identify possible causes of infertility and define a treatment course. Patients use data in a much more emotional way, learning about their bodies while struggling with data interpretation challenges. By analyzing these data practices, we discuss the principles behind their differences and describe how they have individual benefits for each specific group. We then suggest that fertility technologies need to consider such principles, highlight the existing boundary between patients’ and providers’ data practices, and focus on bridging instead of merging them in order to facilitate collaboration and maintain their independent benefits.<sup>1</sup>

CCS Concepts: • **Human-centered computing** ~ Collaborative and social computing ~ Empirical studies in collaborative and social computing • **Applied computing** ~ Life and medical sciences ~ Consumer health

## KEYWORDS

Data practices, self-tracking, fertility tracking, patient-provider collaboration

## ACM Reference format:

Mayara Costa Figueiredo, H. Irene Su, Yunan Chen. 2020. Using Data to Approach the Unknown: Patients’ and Healthcare Providers’ Data Practices in Fertility Challenges. *Proceedings of the ACM on Human-Computer Interaction*. Vol. X, CSCW. Article X (November 2020), 32 pages.

---

## 1 INTRODUCTION

Medical practices are essentially data oriented. The decisions involved in medical work are largely based on patients’ data: data reported by patients themselves during medical consultations, data generated from various laboratory and radiology tests, and data generated from patients reactions to the treatment plans [54,79]. The diagnosis and treatment processes largely rely on data, both clinically generated and patient reported (normally in the verbal format). Lately, with the rise of the quantified-self movement [16] and self-tracking technologies [53], patient-generated health data (PGHD) has been increasingly used in medical decision making and to assist patients in self-

---

Author’s addresses: M. Costa Figueiredo, University of California, Irvine, CA, USA, [mcostafi@uci.edu](mailto:mcostafi@uci.edu); H.I. Su, Division of Reproductive Endocrinology and Infertility Institution, University of California, San Diego, CA, USA; Y. Chen, University of California, Irvine, CA, USA, [yunanc@ics.uci.edu](mailto:yunanc@ics.uci.edu).

Permission to make digital or hard copies of part or all of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for third-party components of this work must be honored. For all other uses, contact the owner/author(s).

© 2020 This is the author’s version of the work. It is posted here for your personal use. Not for redistribution. The definitive version was published in ACM <https://doi.org/10.1145/3432926>

Proceedings of the ACM on Human-Computer Interaction, Vol. 4, No. CSCW3, Article 227, Publication date: December 2020.

managing their conditions outside of clinical encounters. PGHD, which can be defined as health-related data collected outside of traditional clinical settings by patients themselves, brought new types of data to patient-provider interactions.

Prior research on PGHD has studied how self-tracking activities and technologies may influence patient-provider collaboration and individual's own health management. In this paper, we call the practices of collecting and using PGHD as data practices. It is expected that such practices support patient empowerment [4,36], aid healthcare providers in diagnosis and treatment [17,41], and improve the collaboration between patient and providers [17,79]. Nonetheless, prior studies show different challenges patients and providers face when using these data [30], such as different expectations for data use [41,77,90] and conflicting interpretations of the same data [22,43,79]. These challenges suggest that patients and providers may engage in different data practices. More research is needed to understand how providers and patients value and use PGHD differently and how to design technologies to better support their collaboration through PGHD to serve both needs.

In this paper, we study the use of PGHD and its related data practices in the context of fertility with the goal of conception. Fertility is complex, emotionally loaded, and people face great uncertainty when experiencing challenges to conceive. One's fertility journey can involve multiple stages, from trying to conceive on their own to having complex clinical treatments. Fertility is also data centric condition, with use of PGHD throughout the process: patients and providers need data about patients' fertility cycles (e.g., cycle days and results of ovulation predictor kits) to identify ovulation and time intercourse or treatment procedures such as insemination. With increasing use of fertility technologies, both patients and providers have more access to fertility related PGHD. However, it is not clear how they engage in data practices: whether having access to PGHD may influence their use of data, how they may engage with PGHD collection (by patients) and use (both patients and providers), and in case they do not use data in the same way, whether different data usages might lead to tensions and conflicts. It is also unclear whether technologies are designed to facilitate patient-provider interaction based on PGHD in the context of fertility.

We investigate different data practices involved in the context of fertility through interviews with patients facing fertility challenges and healthcare providers specialized in infertility treatments. We draw from Strauss [82] illness trajectory to analyze patients' fertility trajectories and how their data practices are intertwined with fertility-related events, emotions, and interactions with healthcare providers. The findings of the study reveal that patients and providers use PGHD in different ways but with the common goal to explore "the unknown" and deal with the uncertainties intrinsic to fertility. We describe how their data practices are driven by different factors: while providers use data to investigate causes of infertility and define treatments following medical rationality, patients' data practices are embedded and driven by the emotional experiences of their fertility journey. These different practices lead to different value, use, and attitudes towards data. To better support both patients and providers individually and their interactions, we propose that fertility technologies should aim to keep their data practices different, bridging them when necessary. Finally, we offer suggestions on how such technologies could support such bridges.

The study of data practices involved in fertility care has much to contribute to the areas of CSCW, personal and health informatics, and the development of technologies for patient-provider collaboration. It can also help supporting patients' use of PGHD in similar complicated journeys. Our study provides the following contributions: (i) we provide a rich description of how fertility trajectories are diverse and embedded in what our participants called "the unknown," (ii) we report patients' lived experiences with data, including the joys of learning about their bodies and the challenges of interpreting data amidst the uncertainties of fertility, (iii) we contrast the emotional experience of patients' fertility trajectories with the fertility work of healthcare providers, highlighting misalignments and interactions between the two, (iv) we discuss the principles driven their data practices of patients and providers, and, finally, (v) we suggest implications for fertility technologies to better bridge these practices without hindering the benefits of each of them.

## 2 BACKGROUND: FERTILITY TREATMENTS

For many people, conceiving seems a natural part of their life journeys [18] and facing challenges to conceive often becomes a great disruption to their lives [7]. According to a 2004 report of the World Health Organization, around 48.5 million couples were affected by infertility issues [60,92]. It is indicated that couples try to conceive on their own from 6 to 12 months, timing intercourse with the fertile window (i.e., period encompassing the few days around ovulation, when conception is possible [81]). When conception does not happen, they should look for specialists' help, who will use their medical expertise to identify any underlying cause and define the appropriate treatment. However, even with medical specialists' assistance, it is estimated that between 15% to 30% of couples are diagnosed with unexplained infertility because their infertility evaluation tests fail to reveal any biological or physical problem [73]. In these cases, healthcare providers have to treat infertility without knowing the cause. The most common fertility treatments are medications to induce ovulation or superovulation with intrauterine insemination (IUI) and *in vitro* fertilization (IVF) [73]. It is indicated to try the least complex treatment first and increase complexity when the simpler treatment did not result in pregnancy. Fig. 1 summarizes these fertility care methods and treatments in order of medical complexity. It may look as a reasonably straightforward process, but people's lived experiences are often much more complicated.

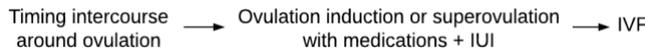


Fig. 1. Fertility care methods and treatments.

Fertility is uncertain and data centric. Trying to conceive can be data-intensive endeavors, particularly when the couple is trying on their own [20,21]: people trying to conceive often track a wide range of health-related data (e.g., cycle days, temperature, ovulation predictor kits' results, cervical mucus, and varied symptoms) to identify ovulation and increase the chances of conceiving by timing intercourse with the fertile window. But even when couples are working with healthcare providers, data generated by patients are still critical for both diagnosis and treatments: fertility treatments require patients and providers to track patients' cycles so they can time the treatment appropriately. This complex relationship between patients, providers, and data makes fertility a suitable context to analyze patients' and providers' data practices in an uncertain context, where the final goal (i.e., conceiving) may not be achievable.

## 3 RELATED WORK

### 3.1 Patient-Generated Health Data for Uncertain Conditions

The widespread use of mobile and sensor devices made it possible for individuals to gather a variety of types of health data. These health-related data collected by patients outside of clinical settings can be called patient-generated health data (PGHD). Self-tracking (i.e., the practice of collecting personal data to reflect on [53]) is currently the primary way individuals get access to these data. Previous research investigated the use of PGHD in the context of complex health conditions in which patients need to deal with the uncertainty of idiosyncratic or unexplained symptoms and inconsistent treatment outcomes. For example, Mishra et al. [64] reported that patients with Parkinson's disease would like to see data about disease progression to plan appropriately. Felipe et al. [29] reported that chronic pain patients saw automatic PGHD collection for symptom detection as a chance to divert their focus from the disease to other aspects of their daily lives. Park and Chen [69] described migraine patients work as "diagnostic agents" to recognize their personalized triggers, and understand and learn how to cope with the disease in their daily lives. In addition, different studies suggest that PGHD activities and technologies can support visibility, social recognition, and self-validation for people leaving with complex conditions [29,57,69]. However,

other studies have reported potential negative effects related to self-tracking and PGHD use, such as feelings of guilt, failure, and stress [2,4,19,25,44]. These studies suggest that exposure to health data may have adverse or negative effects, and people may have both positive and negative experiences when using their health-related data.

Although fertility challenges often do not include an underlying illness, the experience of facing such challenges share characteristics with facing complex conditions: it is uncertain, idiosyncratic, often stigmatized, and present inconsistent outcomes. The rapid growth in the market of fertility technologies [33] increases the need to understand what are the consequences of increasingly interacting with fertility-related data, particularly for individuals facing fertility challenges.

### 3.2 Data in Patient-Provider Collaboration

Extensive research has investigated patient-provider communication in the intersection of CSCW and health. Communication is the primary way through which patients and providers exchange information and, thus, it forms the basis of their collaboration and supports treatment decisions [68]. Effective patient-provider communication has been associated with positive results in satisfaction with care, adherence to treatments, health outcomes, and coping [68,88]. Several studies have analyzed the impact of technology in patient-provider communication during and outside of appointments. For example, Street et al. [83] analyzed the use of electronic health records during clinical encounters, describing patients rate providers communication less effective when they spent more time interacting with the computer than with the patient. Ding et al. [24] analyzed how the use of a mobile social application (WeChat) for communication between patients and providers outside of in-person encounters required negotiation of social and temporal boundaries.

PGHD has been explored as a way to support both patients and healthcare providers. These data are expected to support patients in gaining knowledge about their condition and improving self-management [17,58], and providers in personalizing care, facilitating diagnosis, and defining treatment plans [41,54,90]. In addition, PGHD are expected to support patient-provider interaction by facilitating their collaboration and fostering shared-decision making [17,79]. In this sense, data could connect providers' medical expertise with patients' knowledge about their lived illness experiences [6,79]. However, despite all these potential benefits, past studies have described different conflicts around PGHD use between patients and providers, particularly when patients start tracking data on their own [17,30,41,79]. Often patients and providers have different needs and expect data to be used in different ways [74]. Previous research have described how patient-provider interactions through data often end with both of them feeling dissatisfied, particularly because tools were not designed to support collaboration [17,79]. Patients feel dissatisfied with how and how much providers engage with their data [17], while providers face challenges related to information overload, data incompleteness, time constraints, and accuracy issues [77,79].

Research on patient-provider collaboration have approached these issues by, for example, exploring data sharing during and outside clinical visits [90], or analyzing data sharing preferences of patients and different health providers involved in their care [41]. Schroeder et al. [79] proposed visualizations with different levels of detail to support collaborative explorations of diet data during medical encounters. Similarly, Mentis et al. [62] analyzed how patients and providers craft different views of data during consultations, integrating their data practices through collaborative analysis. Although such body of research provides important insights to the fertility context, to the extent of our knowledge, it is still unclear how the increased use of fertility related PGHD and technologies affects patient-provider collaboration when they are working together during fertility treatments.

### 3.3 Fertility Research in HCI

A growing body of research in HCI has explored varied aspects related to female fertility. Because of its complexity, uncertainty, and the existence of taboos [1], several studies have focused on aspects related to information and emotional needs in, for example, menstrual education [85,86],

menopause [49], and fertility-related diseases such as endometriosis [61] and vulvodynia [89]. Pregnancy has been historically researched in the fields of CSCW and HCI. For instance, studies have focused on how people use technology to search pregnancy information online [37,47], how to prevent excessive gestational weight [71], and how nurses coordinate patient work with documentation work in childbirth [72]. Other studies have focused on experiences after pregnancy, such as breastfeeding in public [5] and using a pump [23]. However, conception is not always easy, and many couples experience challenges when trying to conceive [14,21,70,93], facing stigma and emotional struggles [20,70], often experiencing sensitive and potentially traumatizing fertility-related events such as miscarriages [3]. Although related to conception, such topics have been less approached in the aforementioned fields.

Recently, PGHD are being used to track different fertility-related aspects [27,31,52,56,65]. In particular, Costa Figueiredo et al. analyzed the self-tracking practices of people trying to conceive, describing how the knowledge-intensive and highly personalized context of fertility pushed people to turn self-tracking into a collaborative activity of making sense of personal data [21]. Leveraging the personal informatics model [53], their study described the specific challenges people tracking fertility face in each of its stages. In another fertility-related study, Homewood et al. [38] reported that the ambiguity present in fertility tracking leads to confusion preventing patients from feeling as experts about their bodies. This is aligned with prior studies that described how self-tracking activities are intertwined with emotional experiences, and how the complexity of fertility contributes to pressure and emotional burden [20]. Building on these findings, in this paper, we approach how self-tracking activities influence patients' fertility trajectories, providers' practices, and patient-provider collaboration. We use the term data practices summarizing activities related to the use of personal health data.

This previous body of research suggests that data may play a role in the experiences of people trying to conceive and in their relationships with healthcare providers. On one hand, although prior research has examined the experience of infertility [7], such investigations did not approach the use of PGHD and how it influences people's fertility journeys. On the other hand, studies that have investigated fertility self-tracking with the goal of conception [20,21,38] have not analyzed how these data impact individuals' lived experiences and their interactions with healthcare providers. Our study approaches this gap and describes how patients and providers use PGHD in different ways to explore "the unknown" derived from the uncertainties of fertility. Based on our results, we discuss the principles influencing patients' and providers' data practices, and the value of keeping their practices different while supporting their interactions.

## 4 METHODS

To investigate patients' and providers' data practices related to fertility challenges we conducted in total 19 individual interviews: 14 with people who have faced or are facing challenges to conceive for at least 6 months (hereafter called patients for simplicity of reading and represented by P1 to P14), and 5 with reproductive endocrinology and infertility specialists (REIs) who directly work with patients facing these challenges (hereafter represented by D1 to D5).

### 4.1 Recruitment and Data Collection

We used snowball sampling and partnered with a fertility clinic located in the west coast of the United States to recruit participants to our study. We will not disclose the name and location of the clinic to protect participants' anonymity. All participants verbally consented to participate and received compensation for their participation. Interviews were audio-recorded with participants' consent. Our study was approved by the Institute Review Board prior to data collection.

#### 4.1.1 Healthcare Providers.

After authorization was granted by the clinic and our study was approved by the IRB from our institution, we recruited healthcare providers: all five healthcare providers interviewed in this study were REIs, working in the same clinic. To protect providers' identity, we use a neutral pronoun to refer to them to avoid possible identification based on their gender.

We used semi-structured interviews to investigate providers work practices and their interaction with patient data. This is an appropriate method for such interviews because it allows for openness of responses and for ensuring all aspects of interest were covered. The interview protocol was developed based on an initial meeting with the healthcare providers working in this clinic and a literature review we have conducted. The interviews focused the following aspects: (i) healthcare providers' work practices and experiences conducting fertility treatments, (ii) their attitudes towards PGHD, and (iii) their views of patients' infertility experiences. All interviews were conducted via phone calls or online and lasted from 31 minutes to 1 hour 04 minutes.

#### 4.1.2 Patients.

We recruited patients from the same clinic and through snowball sampling methods using IRB approved flyers. We left flyers in the waiting room of the clinic and asked the healthcare providers we interviewed to give flyers to their patients when they felt appropriate. We contacted the patients referred to us and followed up with the interviews. We recruited 14 patients, including a couple (P4 and P5) who were interviewed separately. We asked each patient if they were willing to refer their partners, if there was one, to be interviewed, but only one partner agreed to participate (P5). Excepting P5, all our patient participants were female. Most of our participants (11) were recruited through snowball sampling, having no connections to the fertility clinic. Although more patients showed interest in our study when providers asked them, only 3 contacted us and completed the study. All 14 patients have tried or were trying to conceive (TTC) for at least six months.

Table 1 summarizes the characteristics of patients who participated in the study listing the main aspects that influence patients' fertility experiences: the age when they faced fertility challenges (Age), how long these challenges lasted or are lasting (Time), the main diagnoses and fertility-related events (Diagnosis and events), the treatments and activities (e.g., tracking) they tried (Actions and treatments), the number of healthcare providers they have consulted (HP), and if they conceived any child (Conceived). Since several participants faced challenges conceiving more than one child, we use "/" to separate information for their first child / second child.

The average age of our participants when they first faced fertility challenges was 29. The average time trying to conceive was 32.4 months and the average number of healthcare providers these patients worked with was 2.5 (both averages consider first and second child attempts). The time to conceive the first child was between 1 and 10 years, while the time to conceive the second was between 1 month and 1 year. Both these times consider the current length of participants' fertility trajectories, which can increase since six participants were still trying to conceive by the time we interviewed them.

Interviews with patients followed a narrative approach [26,42], asking participants to tell a narrative of their experiences trying to conceive. Narrative interviews are appropriated for our study because data practices are intrinsically embedded in people's lived experiences and situated life events. Such experiences are naturally narrative oriented. Narrative interviews, thus, support the investigation of people's data practices by foregrounding the context in which actions and events happen and people's own explanations about them [26,42].

After explaining the context of the project to the participant (initiation phase [42]), the first author used "a generative narrative question" [75] (i.e., can you tell me about your experience trying to conceive?) to invite participants to share their personal experiences with fertility challenges. During this stage of the interview (main narration [42]), the first author actively listened to the participant, signaling attentive listening to encourage the participant to continue the narrative, and taking notes for future questions when necessary. After the participant clearly signaled ending the narrative, the first author asked clarifying questions concerning the events narrated by the

participant (questioning phase [42]), particularly to guarantee a clear understanding of their fertility trajectories. At this stage, the first author also probed follow-up questions when certain aspects of experiences were not described sufficiently by the participants, especially concerning aspects related to technology, major fertility events, and data tracking activities.

Table 1. Summary of participants' characteristics (patients).

P#	Age	Time <sup>a</sup>	Diagnosis and events	Actions and treatments	HP	Conceived
P1	25 / 37	4y 6m / 1y	Endometriosis	Tracking, endometriosis surgery, procedure for cervix obstruction / Tracking	7 / 1	Yes / Yes
P2	36	7y	-	Tracking, conceived 1m before treatment	3	Yes
P3	29 / 33	1y / 6m	Low motility (partner), 1 miscarriage	Tracking, regular exams / Tracking, regular exams	2 / 1	Yes / Yes
P4&P5	29 / 32 / 24 / 27	2y / 3y+	Unexplained infertility, 1 miscarriage	Tracking, 1 IUI / Tracking, 6 IUIs, 1 Mini IVF	2 / 5	Yes / No
P6	28	4y+	3 ectopic pregnancies	Holistic treatment, tracking, IVF	3	No
P7	39 <sup>b</sup>	1y+	Insulin resistance, PCO	Tracking, homeopathic treatment, progesterone treatment	3	No
P8	30	4y+	Fibroid	Tracking, fibroid surgery, 3 IUIs	1	No
P9	30	10y	3 miscarriages, partial mole	Tracking, ovulation stimulation, 3 IUIs, traditional Chinese medicine	3	Yes
P10	32 / 34	1y / 5m+	PCOS, Dermoid cyst	Tracking, birth control to have periods, cyst surgery, IUI / Tracking, IUI	1 / 1	Yes / No
P11	24	2y	PCOS, 1 miscarriage	Tracking, progesterone treatment, 5 rounds of ovulation stimulation	1	Yes
P12	29	1y 6m	Endometriosis	Abortion, tracking, endometriosis surgery, endometriosis medication	3	No
P13	23	2y 8m	PCOS, MODY diabetes, Unexplained male infertility	Tracking, ovulation stimulation, IVF	5	Yes
P14	28 / 37	6y / 1m	Unexplained infertility, 1 miscarriage	Ovulation stimulation, IVF / Tracking	1 / 0	Yes / Yes

<sup>a</sup> "y" stands for years; "m" for months, and "+" indicates the person is still trying to conceive.

<sup>b</sup> P7 is facing challenges to conceive the second child but faced no challenges to conceive the first.

The interviews lasted from 23 minutes to 1 hour 11 minutes. Two interviews were conducted in person, while the other 12 were conducted via phone calls or online. Each interview generated rich descriptions of participants lived experiences and data practices during their fertility trajectories.

### 4.3 Data Analysis

Both provider and patient interviews were recorded and transcribed for data analysis. Two authors read a subset of interviews and met to discuss themes and identify ways of coding the data. In this stage, one main theme emerged from both patients and providers interviews: "the unknown"

generated by the uncertainties related to fertility and how participants use data to understand “the unknown.” Following this main theme, we analyzed patients and providers interviews separately.

*Patient interview:* based on the initial analysis and discussion, we decided to analyze patients’ data using the illness trajectory concept proposed by Strauss et al. [82], which “refers not only to the physiological unfolding of a patient’s disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization” (p.8). Later, Riemann and Schütze [75] generalized the concept of trajectory into a “central category denoting disorderly social processes and processes of suffering” (p.337) which are structured by events that feel out of one’s control. We used this concept to analyze our patient participants’ narratives because we believe their data practices are intrinsically connected with their trajectories. We call these trajectories as fertility trajectories to better reflect the experiences of our participants.

The first author reconstructed each participant’s fertility trajectory based on their narratives. Patients’ narratives tend to highlight the aspects people consider more important because those are the ones they more easily recall, particularly when they are recollecting facts that happened in the past, as it is the case of many of our participants. After discussing a few reconstructed trajectories, two authors identified three main aspects highlighted by patients in their recollections: participants’ data tracking activities, their interactions with healthcare providers during treatment processes, and the fertility-related events participants encountered throughout their trajectories and the consequences of such events. Each patients’ trajectory was then plotted into a timeline, following these three aspects participants self-reported in their narratives (see Fig. 2 in findings for examples).

*Provider interviews:* the initial analysis and discussion prompted to further analysis of providers’ interviews using open coding [15] and focusing on their work practices, their interactions with patients, and their assessment, attitudes, and usages of patients’ self-tracked data.

After analyzing provider and patients’ data separately, the first author then reanalyzed all the data, conducting open and axial coding [15] in all 19 interviews focusing on patients’ and providers’ data practices, and their relation to “the unknown.” Misconceptions, learning, emotional experiences, and relationships with data (patient-data, provider-data, patient-provider-data) are examples of codes that emerged from this analysis. Throughout the whole coding process, the first and third author met regularly to discuss data analysis.

#### 4.4 Limitations

This study has limitations that reflect the challenging nature of this population. Most of our participants have faced fertility challenges in the past but eventually conceived. Patients who are still trying to conceive are less willing to speak out of their experiences for various reasons, such as stigma, stress, or sadness. Also, all our interviewees, but one, are the female partner who would or who carried the baby. Although we tried to recruit the other partners, only one agreed to participate. Therefore, partner views and challenges are not represented in our data. Also, our study focuses on female fertility, therefore, male experiences with infertility are not discussed in this paper (we refer to Patel et al. [70] for a discussion concerning male infertility and experiences). In addition, our patient population was composed by heterosexual cis people, which do not represent more diverse experiences and critical challenges faced by other couples and individuals in their fertility trajectories. The five healthcare providers we interviewed were all REIs and worked in the same clinic. However, patients facing fertility challenges often work with multiple providers from different specialties. It is likely that the practices our REI participants described are not generalizable to the practices of every healthcare provider from every specialty. We addressed this limitation by getting patients’ accounts of their interactions with other healthcare providers, however, it would be useful to conduct further interviews with a more varied group of providers. Finally, although our participants have different ethnicities, they were all, but one, living in the U.S., not representing the broad spectrum of people facing and treating infertility issues worldwide.

## 5 RESULTS

In this section we provide an overview of the fertility process, describing how fertility is entangled with what patients refer to as “the unknown” and describe how this “unknown” is embedded in varied fertility trajectories. Then, using REIs work experiences and patients’ lived experiences, we report how patients and healthcare providers use PGHD in different ways to approach “the unknown,” highlighting how their data practices differ and interact. In reporting these results, when use data or data practices, we specifically refer to the practices related to PGHD collection and use.

### 5.1 Overview of the Fertility Process

#### 5.1.1 A Plurality of Fertility Trajectories.

Fertility trajectories are per se unexpected, since people commonly do not anticipate they will face challenges to conceive, as explained by P10: “*You don’t expect to have these problems and you see it [pregnancy] as just a natural thing that happens. And so, the fact that it doesn’t naturally happen for you, for myself, you feel inadequate.*” People’s lived fertility trajectories are distinct, full of “alternative paths,” and unexpected challenges. Next we present two examples of fertility trajectories from our participants to illustrate the complicated processes and factors that might influence them. All names are pseudonyms.

*Claire (P9) – 10 years of western and eastern medicine:* Claire was 28 when she conceived and had her first miscarriage. After that, she and her partner started actively trying to conceive, but she “*didn’t get pregnant for quite a few years.*” So, she started “*trying to find the reasons that I can probably change [...] to help the process.*” She used a fertility app and a digital spreadsheet, tracked period dates, intercourse, temperature, and monitored her lifestyle measures (e.g., diet), and mood and symptoms (e.g., stress). She conceived again but had another miscarriage. She and her partner then looked for a specialist that did several tests “*but unfortunately, they didn’t find anything wrong. You know, we were hoping that they could find anything wrong so that there is something to fix.*” They kept trying on their own, also using ovulation predictor kits (OPKs), until an exam indicated the presence of a partial mole (a tumor generated by problems during egg fertilization [13]). Because of the risk of a partial mole to become cancer, the specialist suggested stop trying to conceive for a year to monitor Claire’s health. “*It turned out that it was totally benign, there was nothing, and they weren’t even sure if that really existed.*” After that year, Claire and her partner conceived again, facing another miscarriage. They changed their insurance to see “*more prestigious infertility doctors.*” They did three IUI cycles “*along with a lot of tracking, like doing ultrasound every couple of days [...] to basically monitor the whole ovulation process.*” None of the IUIs were successful so Claire ended up “*kinda like giving up on the western medicine*” and decided to try traditional Chinese medicine (TCM). She spent about three years taking herbal medications (“*the herbs, and you boil it and you just take it. You don’t know if that helps, but just pray that it’s gonna help*”), doing acupuncture, and monitoring blood pressure, pulse, and hormones. Eventually she stopped seeing the TCM doctor. She conceived after she almost gave up completely.

*Anna (P11) – obsessing after a miscarriage:* Anna was 24 when she started trying to conceive. She stopped taking birth control, but she did not get a period for many months. Then she started a progesterone treatment prescribed by her midwife, got a fertility book, and started tracking her temperature using a digital spreadsheet, “*just kinda lightly tracking stuff [...]. I wasn’t super committed to it.*” She conceived but had a miscarriage, which was a very difficult experience: “*I had just not even thought that that could happen, and it was a huge shock. For me, it was a super hard loss, and I had a big depression afterwards.*” She became afraid she would not be able to conceive again: “*who knows where these thoughts were coming from, but it was just a lot of fear.*” At some point, she had to return to birth control because she had recurrent bleeding, “*which was really frustrating to me because I was like, ‘no, I’m trying to get pregnant. I don’t wanna be on birth control pills.’*” The miscarriage experience led her to track more, trying to understand the causes and avoid other miscarriages: “*that’s when that [tracking] really, really intensified, and I*

started to use the software. I was tracking all of my symptoms. I was tracking my temperature every day. I was tracking my periods and intercourse and everything.” She also tracked cervical mucus, cervical position, symptoms, OPK results, and medication. “I was using that [software] for months. I had months and months of data; I got really obsessed with it.” She also started a treatment with medications to stimulate ovulation, prescribed and led by her midwife. She did five cycles of ovulation stimulation alongside tracking, until she finally conceived: “it was interesting because [...] the cycle that I got pregnant [...] it didn’t seem like I ovulated. [...] I never ovulated, according to the software... but I still got pregnant.”

Fig. 2 summarizes Claire and Anna’s fertility trajectories. These two participants were young when they first started having fertility challenges, younger than the age fertility is typically expected to decline [73,94]. Their trajectories have different lengths; while Anna conceived in two years, it took 10 years for Claire to conceive. Fig. 2 also highlights the different healthcare providers they worked with (REIs, TCM doctor, midwife), the different treatments they tried (IUI, ovulation stimulation, TCM), the various fertility-related events they experienced (miscarriages, partial mole), and the intense tracking activities they performed.

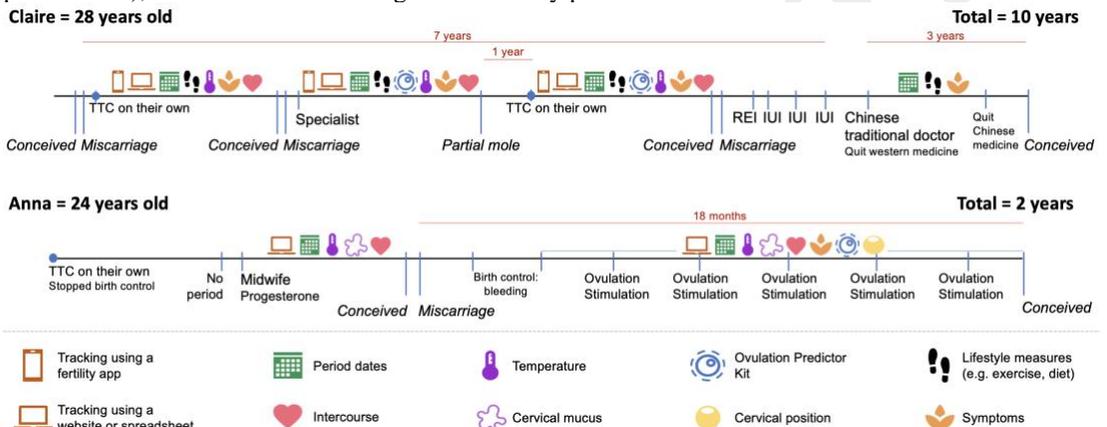


Fig. 2. Claire’s and Anna’s fertility trajectories

Claire’s and Anna’s cases are not common or typical: every fertility trajectory is different with unique experiences and challenges. For example, P1 visited five different healthcare providers who dismissed her painful periods until being diagnosed with endometriosis. P3 did not know anything about tracking until her OBGYN told her to track OPKs and temperature. She used these data to conceive three times, with one miscarriage in between pregnancies. P6 engaged in intensive tracking and worked with different healthcare providers to try to conceive “naturally,” but after facing 3 ectopic pregnancies she decided to move to IVF. After having the first child without difficulties, P7 engaged in intensive tracking, using up to 5 fertility apps, to try to conceive her second child. P8 tried initially on her own using tracking, then she did three cycles of IUI alongside tracking, which did not result in pregnancy. P14 had her first child through IVF after 4 cycles of ovulation stimulation and 6 years of trying. She had a bad experience with the IVF treatment and turned to tracking to conceive her second child.

A common aspect of these experiences is the presence of tracking. All our participants performed some level of tracking and engaged with their data. Data tracking, either by apps or by other means, plays an important role in people’s fertility journeys. As illustrated by Claire’s and Anna’s trajectories summarized in Fig. 2, participants use a variety of tools to track a variety of health indicators, starting, changing, intensifying, or reducing tracking in different moments of their journeys. Claire’s and Anna’s cases also illustrate how people’s data practices are directly connected to the complexity and uncertainty of the fertility context. Claire used tracking throughout

the years to try to identify the reasons why she was not getting pregnant. Anna intensified her tracking to understand the reasons and try to avoid another miscarriage. In both cases, the end goal (i.e., pregnancy) was uncertain, no matter how hard they tried. All of our participants faced similar uncertainties, leading them to “resort to these [data practices], kinda trying to make sense out of... nothing because there’s just such little information” [P11]. Patients used their data practices to deal with some of them called “the unknown” every step of the way.

### 5.1.2 The Unknown.

Fertility is extremely complex, involving intricate hormonal processes not completely scientifically understood [81]. This complexity creates a lot of uncertainty for healthcare providers and patients.

The main uncertainty for providers comes from the fact that the mechanisms of fertility and the causes of infertility are not completely clinically understood. The field of Reproductive Endocrinology and Infertility is still considerably new, and many of the current medical tools and processes are recent. For example, D4 explained that ovulation predictor kits (OPKs), which are the most reliable tests to detect ovulation, are a recent development: “it’s really just been my generation—the last 30 years I would imagine—that we had a kit [OPK] to detect it [ovulation].” Besides, the diagnosis process naturally involves uncertainty. For example, as D1 exemplified, even OPKs may not be 100% accurate: “so particularly in patients that have polycystic ovary syndrome [PCOS—a hormonal disorder that may impact fertility], there is a risk of false positive ovulation predictor kits. But we don’t know – that doesn’t happen in everyone that has PCOS.”

Additionally, it is not uncommon that physicians, even REIs, cannot identify the cause of infertility. All our REI participants described seeing patients with unexplained infertility in their daily work. D3 explained that these patients are especially difficult to treat because the cause of their infertility may be due to factors that our current medical knowledge cannot recognize: “the patients who are more difficult are the unexplained patients, because they may have some type of implantation factor [a factor impacting the attachment of the egg to the uterus] or something that we don’t have the means to test for yet” [D3]. If the patient has unexplained infertility, healthcare providers need to define treatments to achieve pregnancy without solving its underlying causes.

These complexity and uncertainty are even more challenging for patients. Because of them, patients facing fertility challenges commonly experience a feeling of groping in the dark and lack of control. Similar to findings of previous studies [21], the uncertainty of fertility comes from many factors. For instance, every patient is different, so people cannot directly compare with others (e.g., “you see somebody say ‘Oh, I used this product and got pregnant the first time.’ And then, you are like, ‘Oh, well I’ve used it for a year and it hasn’t worked.’” [P4]). The fertility cycles for a single person can vary from month to month (e.g., “I had some cycles where it would range anywhere from 36 days to 58 days. [...] The variables are so different on a cycle by cycle basis” [P10]). Identifying the fertile window involves indicators that can be uncertain, subjective, or difficult to interpret (e.g., “I see there’s a change in my resting pulse rate, but what does that mean? Does that mean during ovulation? Does that happen after ovulation? Does that confirm my ovulation? Does that mean it’s coming?” [P7]). Also after having intercourse, patients often use different data to try to identify if they have conceived, in a period before it can be measured through a pregnancy test (e.g., “I would spend so much time comparing my chart to the charts in the forum [...] because there’s that time after you ovulate where you’re like, ‘I might be pregnant’ or ‘I might not be pregnant,’ so that would be the really stressful period” [P11]). All these factors add to the clinical uncertainties of fertility and make the whole experience very complex and uncertain.

Amidst all these uncertainties, many participants explained that the biggest challenge of their fertility trajectories is dealing with “the unknown of everything” [P3], which is generated by the uncertainty of not knowing what is wrong or if treatments will work. P9 summarized the general feeling of facing fertility struggles for over many years: “Just the unknown. Like you never know what’s the end result because nobody can give you an answer, or give you like a plan, and you just follow this plan and it’s gonna happen. Or it’s all gonna be fine after how long. Nobody can give

*you a clear explanation or a definitive answer. So you basically, you are just going but not knowing the direction or the light. You don't know where is the light. Yeah. So, it's just unknown.*" The unknown resulting from this uncertainty is often the hardest part of patients' fertility trajectories.

Our findings suggest that both healthcare providers and patients use data to approach the unknown, whether they use it to identify the possible causes of infertility, to identify the fertile window, to decide on potential treatments, or to choose follow-up treatments. However, our findings also show that patients and providers engage in very different data practices: they use and value different data and develop different relationships with these data. The next sections will describe how these data practices differ.

## 5.2 Living with Data: How Patients Use Tracked Data to Explore the Unknown

Our findings show that people often use tracking to explore the unknown, believing that gathering and analyzing data will help them understand the unknown and give them the chance to act towards their goal. However, living with data can be more complicated than expected.

### 5.2.1 Types of Data Valued by Patients

Patients try to track different data in order to enhance their chances of conceiving. This includes basic fertility-related indicators, such as period days (tracked by all 13 female participants) and intercourse (tracked by 6). It also includes tracking ovulation to identify the fertile window, which can be done using different methods: 11 participants used OPKs, 9 used temperature, 6 used cervical mucus, 1 used cervical position, 1 used pulse, and 5 used general symptoms. People also track to identify if they conceived using different methods; the ones our participants directly mentioned were general period days, temperature, and symptoms. Participants also mentioned tracking period flow (1), menstrual pain (1), and medication (2). They tracked different combinations of these types of data in different moments of their trajectories. Some of them start tracking on their own, searching online, reading books, or following indications of friends. Others start tracking following healthcare providers suggestions. They performed these activities using paper, websites, digital spreadsheets, fertility apps, wearables, or a combination of these.

In addition, fertility tracking as performed by our participants also involves analyzing and tracking multiple lifestyle factors, such as stress, diet, and exercise to try to increase their chances or to find the reason why they are not conceiving. Seven participants directly mentioned analyzing those. For instance, P9 turned to lifestyle measures, trying to find possible causes for why she was not conceiving and hoping that by acting on them she could increase her chances: *"I just feel that maybe I was too skinny, or I was too stressful. My work is giving me too much pressure. So, I was trying to find the reasons that I can probably change to make it better, to help the process."*

Tracking becomes a way to explore the unknown: participants use data in an exploratory way, tracking new measures and lifestyle practices over time, trying to triangulate the data to increase their chances of conceiving amidst the uncertainty of fertility. P7 described a clear example of using data to explore the unknown, explaining she was *"slowly adding stuff. It was more like every month that ticked by, I kinda needed a greater sense of control, so I was the one that was like, 'Okay, I'm gonna take my body temperature, and I'm gonna buy something else to help me feel like I can control this, I can be in charge of this."* She even used multiple apps (5) at the same time to store and analyze her data, and to compare the different feedback they provided: *"I was like, 'I'm gonna cover all the bases.' Do you know what I mean? What's lining up?"* [P7].

Amidst all the uncertainty of fertility, tracking becomes a way to find *"some information and some kind of hope"* [P13], to get *"some sense of structure"* and avoid the feeling of *"roaming aimlessly"* [P10], and to cope with the emotional toll of dealing with the unknown: *"but because of the way [...] I deal with uncertainty through information-seeking, I actually think it was a way that I was able to stay calm and maintain some sense of control, even though it was sort of a difficult time"* [P11]. Seeing and interacting with data increased participants' sense of control because it gave them a feeling of acting to turn the unknown into known.

### 5.2.2 Using Data to Learn about the Body

Patients explore varied data practices to try to approach the unknown. When they put these data activities in practice in their daily lives, they often need to face an intense learning process, which arouses their curiosity. Patients described tracking can be “*really fascinating*” [P1] and they enjoy learning about their bodies, as described by P11 in the following quote: “*When I first started reading it [fertility book] and tracking, it was really cool because I felt like I was learning about my body in ways that I never had before. Like, I had never known about the differences in cervical fluid for times of the month [...] I had never been that in touch with my body and my cycles before, so that was actually really fun*” [P11]. Similar to P11, many participants felt they did not know much about their bodies before trying to conceive and they wish they have learned more when they were younger, as explained by P7: “*all this information really could have been taught to me much younger, and it would have been much less confusing. [...] To have this kind of insight about your body is not something that should be a luxury, right? It should be taught.*” [P7].

These examples suggest that the female body was in itself unknown to our participants; most of them did not know how their fertility manifests in their body over each fertility cycle before they encountered fertility challenges. Tracking allowed participants to learn aspects about themselves and their bodies and enabled them to understand some parts of the unknown; parts that they could have learned when they were much younger, but they did not probably partially due to the social taboos entangled with female bodies.

### 5.2.3 Challenges of Self-Interpreting Data.

Participants generally enjoyed learning about their bodies through tracking. However, tracking bodily measures can also present challenges. As P3 highlights tracking “*is really quite fascinating but they’re also kind of tricky.*” Data interpretation was not as straightforward as some participants expected; especially considering these data practices are immersed in their daily lives.

Previous studies [21] reported that many measures related to fertility involve subjective analysis. Our data is aligned with these results and our participants described how some measures required time to understand and recognize (e.g., “*the cervix [...] took me several months because to feel your cervix in these different positions was difficult for me [in the fertile days the cervix should be soft, high, open, and wet]*” [P11]). Other measures require strict steps to be collected, which are hard to fit in a person’s life routine. For instance, temperature was the one that generated most complaints among our participants, because it requires daily measuring, normally at the same time in the morning, before getting out of bed, and after having reasonably regular hours of sleep. To some of our participants, these demanding requirements to collect data created “*all these variables that were just like user error*” [P7]. These possible variations in data collection challenge data interpretation. P9, who used an app and spreadsheets to plot her temperature, explained that the complicated process required to collect the data creates noise that hinders data analysis: “*It always has some noise, so to speak, so when you wake up one morning, maybe you ate too much the night before, and your body temperature will be affected. So there is a lot of noise in your data. It’s not easy sometimes because, you know, the temperature doesn’t show the pattern anymore*” [P9].

Similar interpretation challenges also happened when tracking other measures. For instance, P7 described she could not find a pattern in her OPK results: “*the first month, I was like, ‘Oh, [the peak was on] day 15. Perfect. Life is great.’ And then, the next month I got no peak, and then the month after it was 12, and then 10, and then 20, and 17, 13. I mean, it was just – it’s hard.*” P10 also faced problems with OPK, but instead of facing variability in the peak day, P10 actually never got a peak. Instead, she got 15 days of high fertility for multiple months, which was confusing and exhausting for her and her partner: “*That blinky smiley face [high fertility indication] was 15 days long and I never got an ovulation day. [...] And I never got pregnant for those three months. And based upon the length of my cycles, it honestly got very frustrating. We were just like, ‘Okay, we*

*must've gotten the window,' and it was like we got sexual fatigue. Where even my husband's like, 'Can we take a break?' I was like, 'Yes, we can totally take a break'" [P10].*

Not being able to identify a pattern through tracking confused and frustrated many participants. Some started tracking more data, others acted without knowing precisely when their fertile windows were. The latter led to sexual fatigue and no pregnancy for P10 and her partner. To P12, it impacted her sexual experience with her partner: for some time, the data became so important to her that her sexual activity was focused on them. She described she *"tried to have intercourse in that period [fertile window]. And sometimes I finished it [intercourse] and then I went to the app to make notes, so it was not good."* As these examples show, these tracking activities directly impact people's daily lives. Living with data often turns to be confusing and complicated: the data are often imperfect, take too much effort to collect, are difficult to understand, and do not tell people why they cannot conceive even if they track everything they can.

#### 5.2.4 The Unknown Remains Unknown.

Patients turn to tracking hoping data will help them to approach the unknown, they will be able to understand fertility better, and use this knowledge to conceive. However, that is often not the experience they have. Besides all the challenges of tracking, having data does not mean understanding, especially in a context so naturally uncertain and largely still unexplained as fertility. P4 explained this interaction between data and hope using the analogy of a rollercoaster: *"It's [an] emotional challenge of being on a rollercoaster of uncertainty. So, it's an emotional rollercoaster, really. For the first two weeks, you work really hard. You're excited. You're going to do it. And then, for the last two, you really don't know. And then comes the result. So – oh, that uncertainty – it's huge. It's a big challenge"* [P4].

More so, data may even intensify this rollercoaster experience, as explained by P12 who would compulsively check her data while her hopes got high and down during the cycle: *"You did your job, you got a good probability of being pregnant, and you are in the middle of 2 periods. And your period should come in the day 2 and then it doesn't come. And it is day 5. Then I start to check [the fertility app] almost compulsively and when my period comes it makes me feel sad, makes me feel nervous, makes me feel stressed. It wasn't very good for me"* [P12].

Patients' data practices are often not only involved but driven by their emotional experiences. Some participants add more measures every month hoping to increase their chances of getting pregnant (e.g., *"every month that ticks by, you get desperate, right?"* [P7]). Others experience undesirable fertility-related events (e.g., miscarriage, ectopic pregnancy, partial mole) that negatively impact their emotional experiences and their data practices, as exemplified by P11: *"I think my tracking probably would have been much more just in sort of, 'this is fun and interesting,' if I hadn't had the miscarriage first. I think that having a miscarriage really – that was such a difficult event for me. I grieved a lot and I became really depressed about the loss. I think that then sometimes the tracking became one way of kind of obsessing about that. You know what I mean? Like, 'will it happen again?' I was really scared about that"* [P11]. Such events increase patients' emotional toll, affecting their data practices and their relationships with data.

Together, the disappointed, unexpected, unpredictable, and undesirable experiences most of our participants experienced also remind them that, even after intensive tracking, the unknown remains unknown. P4 described how this constant uncertainty is bewildering, since no matter what patients do there is no guarantee to have the expected results: *"That uncertainty is so challenging because for a lot of us – regular people – you work at something and you get results, right? So, it's cause and effect. It's just like that. And with this, with fertility, it's not cause and effect. You do everything by the list that you have to do, and still doesn't work"* [P4].

Some patients realize that they cannot really control fertility but still kept tracking because of the benefits of learning, having a plan to follow, and gaining some sense of control. For example, P11 described her obsession with data worked as a coping mechanism: *"and I think tracking, honestly; the kind of obsessive tracking was, in a way, my weird way of controlling, of exerting*

*some measure of agency in an uncontrollable situation.*” Others abandoned tracking because they felt tired or too obsessed (e.g., *“at one point I feel like tracking makes me too stressful, like thinking about it too much. So I would give myself a break”* [P9]), because they felt it was not accurate and did not give the results they expected (e.g., *“what I have not been consistent is just I think after so long, it didn’t seem reliable anymore”* [P8]), or because they felt they have learned everything they could (*“I’ve tracked for so long now that I can tell you, the third week of my period, I have insomnia. [...] I don’t need a tracker to tell me this stuff anymore”* [P7]).

In summary, engaging with data to explore the unknown by patients themselves can be a fascinating learning experience. However, the experience of living with data can also be particularly challenging, especially when people’s tracking experiences are embedded within and fed by the emotional rollercoaster of trying to conceive. Even those who conceived often do not know why it happened (e.g., P9 who conceived after 10 years when she was almost giving up), and many others may remain in the dark with extensive data that may not lead to their goal.

### 5.3 Working with Data: How Providers Follow the Decision Tree to Treat Patients

Patients from our study described seeing and working with various healthcare providers with different specialties. In the trajectories presented earlier, Claire and Anna described seeing REIs, a TCM doctor, and a midwife. Other providers our participants worked with include OBGYNs, OB nurse, holistic doctor, fertility acupuncturist, homeopathic specialist, and metabolism specialist. The reasons why people choose such a wide variety of healthcare providers vary: desire to try natural approaches, a previous relationship with the provider, a referral from another provider, and insurance issues. REIs are usually one of the last resources patients look for because they are specialized in infertility treatments, which are more complex, more expensive, and often involved in stigma (e.g., *“It was the only time I went to a doctor who said that she has knowledge specifically about infertility issues. And I said ‘ok, well I don’t know if I have infertility issues, like, this big word ‘infertility’, but I am certainly having period problems’”* [P1]). Unless patients are aware they have infertility factors, they may not consider REIs. As such, REIs usually enter patients’ trajectories after they have tried different providers and tracked varied fertility-related data.

#### 5.3.1 Types of Data Valued by Providers

Similar to patients, healthcare providers also need data to approach fertility. Healthcare providers work mostly with three types of data: 1) patients’ answers to their questions, particularly medical history and symptoms (e.g., *“so medical diseases, medications, allergies, surgeries before, supplements that they may be taking, social history”* [D4]), 2) radiology tests (e.g., *“we want to make sure to get a HSG [hysterosalpingogram], which is an x-ray, to make sure their tubes are open”* [D3]), and 3) laboratory tests (e.g., *“we do a semen analysis and then we see if the periods are regular in the female partner and if they’re irregular we do some blood tests such as thyroid”* [D5]). These data are used by providers to determine a treatment path. Radiology and laboratory tests are often used to confirm what patients reported and to explore possible factors for infertility, as explained by D1: *“then other helpful things after I know that [menstrual history] are to do an ultrasound, to look at the ovaries and the uterus, because that can give me more details to explain why their menstrual periods are occurring the way that they’ve described.”*

Other than the radiology and laboratory data that are gathered in the clinical settings, providers largely use PGHD. Patients’ menstrual history is critical information for providers and they generally value patients’ tracking data for this matter, as explained by D1: *“I think they [fertility apps] are actually really helpful for that main intake of history, because if we have someone coming in for an evaluation for infertility and they don’t have any of that information, it sort of delays their evaluation a bit, or makes their evaluation more difficult, because without tracking, they can’t really answer that question about their menstrual cycle. And I think that’s one of the most important starting points in evaluating someone who’s trying to conceive. So, it’s really helpful”* [D1].

Besides the initial history, REIs also need PGHD to identify ovulation patterns. As the previous quote suggests, if patients already have tracked data that indicate ovulation, it may save them months, since these data can help providers in identifying ovulation patterns, a necessary step to proceed with their evaluation and treatment decision. In cases where patients have never tracked ovulation before, or in cases where they have irregular cycles, it is common for REIs to ask patients to track for a few cycles, as explained by D2: *“so, patients who cannot recall menstrual pattern or who seem to have long menstrual patterns, we ask them to track [...] the beginning and the stop dates of their menstrual period. And if they do use LH kits [OPKs], to track the results.”*

However, as this quote indicates, REIs consider and ask for only a few types of data, mainly period dates and OPK results. Other data tracked by patients are often not viewed as useful from REIs' perspective. For instance, while many of our patient interviewees attempted to precisely measure and understand their temperature data, these data were often considered controversial by the REIs because it does not work for everybody (which is aligned with the challenges patients described): *“it doesn't work for everybody, just like the ovulation predictor kits don't work for everybody, but I pay attention to that. [...] But if they were able to track their temperature and they have a clear spike in the temperature, that's useful information”* [D5].

Similarly, cervical mucus, another type of data valued by patients, is considered *“nonspecific”* [D2], *“not reliable”* [D1], or *“subjective”* [D3], by the REIs we interviewed, and they do not use it. D4 explained that these measures were probably more useful when more precise data and tools were not available, describing it is still good to know that patients identify fertile characteristics (color and consistency) in their mucus, but D4 does not use these data: *“I think in the past when we didn't have the ovulation predictor kits, it [temperature and mucus] was more helpful. And certainly, knowing that they [patients] get the egg yolk, thickening cervical mucus, it's good things to hear. But I already know from other information whether they're ovulating or not”* [D4].

These examples suggest that providers emphasize controlled and objective data, which are expected to have better quality and reliability. They also show that, the ability to explore the unknown is different for healthcare providers since they have more medical knowledge to interpret the data, and can access tests' data using medical procedures that patients cannot access.

### 5.3.2 Using Data to Follow a Protocol

Applying their expert knowledge and their training, healthcare providers' use of data follows a protocol that maps a series of related choices and their possible outcomes. This protocol starts in the first appointments, when healthcare providers gather patients' medical and fertility history. D4 explained that in these initial appointments they need to check mainly four aspects from the couples' health history: *“When I initially speak with them, I talk with them that we really think about four categories that contribute to a couple's fertility, because infertility is a couple's disease. And that's eggs—egg quality, egg quantity—sperm quality, reproductive anatomy—so, uterus, fallopian tubes, ovaries. And then the last category, which is most pertinent to the apps, is ovulation, and whether ovulation is occurring, whether it's reliable, predictable, in a pattern.”*

Based on the data gathered from the initial conversations with patients, providers conduct subsequent radiology and laboratory tests and follow a protocol to define the treatment together with the patient. If they find an underlying cause for infertility (e.g., tubal occlusion) they follow the indicated treatment for that pathology, as explained by D2: *“that just depends on what their diagnosis is, right? So, if it's not ovulatory, then you need to use medicines to make them more ovulatory, and that's different from someone who has male factors and low sperm, then that takes you down the path of finding sperm.”*

Despite having access to data from medical tests and procedures, having expert knowledge, and having a clear protocol, infertility can still be unexplained for healthcare providers, as explained by D1: *“So, basically, all of the things that we look at will be normal. And that's how we end up at the unexplained infertility diagnosis.”* In this case, healthcare providers resort to the three main possible paths as explained by D2: *“It's a discussion of what is the anticipated fecundability with*

*attempting unassisted versus what is the fecundability with using Clomid [drug to stimulate ovulation] and insemination as treatment versus IVF as treatment.”* In addition, D5 reported that in such cases it is necessary to consider not only the complexity of the treatment but also factors such as cost and stress and patients’ preferences: *“Usually the rule of thumb is that we start with the least invasive and least expensive and least stressful treatments and then we go up. But I always tell patients that I provide information and the choice of treatment is ultimately theirs.”*

Complexity, cost, and stress, alongside risk and success rates, compose some of the main considerations involved in treatment decisions. In the following quote, D4 explained that the rationale for prescribing IUI or IVF is based on scientific data: *“Generally, success with the superovulation IUI cycle is around 12% across clinics. But success with an IVF cycle is, depending on the women’s age, anywhere from 40 to 60% generally. [...] We recommend to go straight to IVF for tubal occlusion or a tubal cause of infertility. But for other causes of infertility, I think it’s appropriate and ethical to recommend that couples try superovulation and IUI first. But the benefit of superov and IUI really starts to go down after four cycles of trying. And so, my recommendation is three to four cycles of superov IUI, and if not pregnant, then we need to discuss IVF”* [D4].

In this quote, D4 emphasized that after a number of attempts, some treatments have lower probabilities of success and it is not worth trying them anymore. Sometimes, healthcare providers follow their whole protocol, do all the tests, and try all available treatments, but their patients do not conceive. At some point keep trying becomes non advisable. D2 explained that this point is defined by the likelihood of pregnancy considering patients’ whole fertility trajectory: *“there are guidelines and committee opinions about what you define as ‘futility infertility treatment.’ And so, if you think that the likelihood that they’ll have a baby from a particular treatment is less than I think 2 or 1 percent, you can call this medically futile [...]. If you feel like the chances are so low, then it is time to stop.”* D2 explained how they tell patients they are not able to help: *“I explain what are the potential fertility treatments that exist and what is the likelihood that with each of these fertility treatments that they are going to be successful in having a healthy baby or having a baby. Then if that chance is really very low, then the counseling is you can see that even though there is a lot of technology, currently this technology will not increase your chance of being able to have a baby over trying on your own. So, therefore, although it is possible that we undertake this technology, I don’t recommend it because we’re not helping you”* [D2].

These examples illustrate how REIs follow a protocol guided by scientific knowledge and probabilities to define their course of actions. Their actions are driven largely by medical rationality, instead of by lived and personal emotional experiences and personal hope.

### 5.3.3 Challenges Working with Fertility Data.

Our REI participants reported that a smaller portion of their patients (*“probably 15%”* [D4]) seem to get obsessed with data tracking, collecting several months of data for multiple health indicators, as explained by D4: *“I’ve had several patients come, and they have literally an Excel sheet of data. And they’ll say, ‘this is the length of my menses this cycle. This is the number of days that I’ve bled.’ And they’ve tracked the last 12 months. And, ‘this is the consistency of the bleeding. This is my basal body temperature. This is my cervical mucus. This is my ovulation predictor kit. This is my days of intercourse.’ I mean, so they literally come in with this Excel data sheet”* [D4]. However, this level of detail is not helpful for REIs’ data practices. The data they need is more defined and summarized, which is often better captured through a conversation than simply checking months of data points, as exemplified by D1: *“Some people also track [...] the number of days that they bleed. [...] For people that have irregular bleeding for some reason, like intermenstrual spotting, the number of days of bleeding can kind of be helpful, but in general, that’s not more helpful than someone just saying, ‘I bleed between periods,’ or ‘I have heavy periods.’ So, I don’t find the number of bleeding days very helpful”* [D1]. Similarly, D3 also highlighted that collecting and analyzing months’ worth of temperature data is difficult for them and for patients: *“I think it’s harder for me to interpret that data when they come in and they have their temperature logged for*

*a whole month. [...] Also, I discourage using that method [temperature] because I think it's a lot of work for the patients. I don't think it's necessary and I think there's other easier ways.*" As these quotes show, healthcare providers face challenges when patients bring extensive data to them because although they do not use them, they need to respond to patients' requests.

#### 5.3.4 Challenges Working with the Unknown.

On top of the challenges with interacting with patients and their self-tracked data, healthcare providers still have to deal with the fact that fertility remains largely uncertain. For instance, their tests may be more reliable than patients' data practices, but they also can fail, as described by D4: *"Unfortunately, even women that are ovulating, about 10% of women will have a false negative with the OPKs, meaning that they are ovulating, but the ovulation predictor kit doesn't detect it. So, that's frustrating for those women. And in that case, we know the OPKs aren't reliable, and we have to do other things in the office to determine when they're ovulating"* [D4].

Unexplained infertility implies that the causes of infertility are unknown. Providers can potentially keep doing more tests (e.g., *"it may be explainable if we did a lot more invasive testing. IVF is a treatment, but it's also, in a way, a test, because it lets us see in a media dish in the lab how these eggs are fertilized by the sperm."* [D4]), but often it is not advisable or possible because of ethical, financial, or emotional reasons. Many patients have difficulties understanding that it may not be possible to find a cause of their infertility. D1 explained that many of them turn to REIs looking for a cure and they become devastated when treatments do not work as they expect: *"I think people come in to see us because they were having trouble getting pregnant, and I think that they assume that these treatments are more like cures. And so, if they undergo a treatment and don't become pregnant, it's kind of devastating, because even when we talk about the likelihood of success, they're still hopeful that it will work, and it's really hard, I think, to accept when a fertility treatment is unsuccessful even when the objective things that we look at are promising"* [D1].

Patients feel frustrated when treatments' results do not match their expectation, which is in part connected with misconceptions about fertility (e.g., *"people overestimate the likelihood that women become pregnant every month. [...] There are [also] misconceptions on the probability of success with different fertility treatments. Meaning I think it's overestimated"* [D2]) and with their strong emotional connection with the goal as D1 explained: *"Well, I think once you tell people that, they understand it, but it's still hard to change the emotional connection they have to that belief, so that's one thing that's sort of difficult"* [D1].

In summary, providers engage with data to explore the unknown in a much more direct way, following a protocol rooted in medical rationality and scientific research. They value PGHD for history taking and for identifying patterns in ovulation so they can define the best treatment course, facing challenges when patients expect them to use extensive data that do not fit their practices or when patients do not understand that treatments are not a cure or a guarantee of pregnancy.

## 5.4 When Different Data Practices Interact

Patients and healthcare providers engage with different data practices to approach the unknown intrinsic to fertility. Even when patients visit healthcare providers before starting their efforts to conceive, they usually start their fertility trajectories on their own. REIs are sought much later in their trajectories, when patients have already worked with other healthcare professionals and often developed consistent and potentially extensive data practices of their own. REIs approach data based on their training, expertise, and experience practicing medicine. When they start working together, the interaction of these two different data practices (which are entangled with the inherent challenges and uncertainties characteristic to (in)fertility) may lead to series of tensions and conflicts. Such conflicts can be further exacerbated by the recent popularity of fertility tracking technologies and individuals' emotional engagement with data [20]. Below we describe the types of tensions reported by our participants and ways to overcome these issues in practices. Since all

providers we interviewed were REIs, we also use patients' accounts of their interactions with other healthcare providers to describe conflicts and positive experiences.

#### 5.4.1 Understanding and Adopting Providers' Fertility Protocol.

When patients and providers interact, patients encounter providers' data practices, often for the first time, and they need to understand how their data are used following the medical protocol. Our data suggest that when providers do not explain how they make decisions and what data they use to make such decisions, patients feel disappointed and confused. For example, patients described providers suggesting treatments without explaining the rationale behind the decisions, which may lead to distrust and misunderstandings between patient and provider. For instance, P7 explained that the first provider she worked with did not explain the connection between the treatment decision with her test results and personal data, which sounded to her as he was considering a more complex treatment that was not necessary: *"he finally got back to me like, 'okay, you have low progesterone. Would you like to try Clomid?' And I mean, at the time, I didn't understand his reasoning. Now I understand his reasoning. But at the time, I was like, 'I have low progesterone. You're telling me [to use] something that's gonna stimulate ovulation. You're wrong. No, I'm going to someone else'"* [P7]. P7 later consulted with another healthcare provider who proposed the same treatment, but, unlike the previous one, this doctor explained the decision-making process clearly and how the decision was connected to the data (i.e., test result): *"[he said] 'the insulin resistance is throwing off your hormones, and every month, you're not ovulating. And that's why your progesterone is low. If we can get you to ovulate, your progesterone will come up.' And I'm like, 'oh, that's why that first doctor recommended Clomid because Clomid will stimulate ovulation,' And so he's just like, 'If we can get the ovulation happening, then the progesterone will get there.'"* P7's reactions with the same treatment plan demonstrate the importance of explaining the decision rationale to patients, especially how data were used, as the protocol used to guide providers' practices are largely hidden to patients.

Some of our participants went along with the information provided to them and followed providers' instructions despite not having sufficient explanations. For example, P4 and P5, who are partners, had an experience with an REI who recommended an IUI treatment without explaining his decision-making process: *"Our first meeting with him threw us off a little bit [...]. [He] didn't really listen to as much about what we had gone through prior. It was just – he came in and knew what needed to be done already. But our treatment there worked, so we can't really complain"* [P5]. His partner, P4, echoed his negative impressions, describing the REI came to this decision very quickly, in the first appointment, without asking for new tests or data, and without providing any explanation of what led him to the treatment: *"the first time we met him, he was very sure about what was going on, which shocked me because he didn't know much about our case. We had just met him 10 minutes before. [...]. I did not have a good impression just because he was very forward, very like, 'Oh, I know what's wrong.' And he had just barely met me. [...] How can he know if I haven't had any test done with them yet? But he's the one that helped us have our son, right? So, you've got him some credit."* [P4]. As both quotes indicate, though the treatment eventually worked, P4 and P5 felt confused, shocked, and doubtful about the provider's decision throughout and even after the process, largely because he had not explained what made him come to such decision or how it was connected to their data (e.g., previous tests or personal data). In P4 and P5's case, although the treatment was successful, their experience may not have been ideal. Treatments often last long, and it takes time to see the results; not explaining the rationale may negatively impact patients because they may feel increased anxiety during the process.

Since patients are less familiar with providers' decision-making process, and may have less fertility knowledge, when providers do not explain how they use data and what data is useful for them, patients feel frustrated when providers seem to not use their data. Sometimes, patients even feel that their prior, painful personal experiences were ignored and not valued by providers. For example, P13 reported that because her case was complicated (involving both male and female

infertility factors), providers seemed to only care about “*their statistics:*” “*I talked to a couple of doctors who were terrible and essentially said, ‘you’ll never have a kid. You and your husband are both... It’s not gonna work,’ and all but I said that we would hurt their statistics*” [P13]). Finally, the fifth provider she visited demonstrated more empathy with their case and considered they had around 10% chances of getting pregnant. She did an IVF with that provider and conceived.

When the decision-making process and the inherent data practices were well-explained to patients, they were more satisfied and trusted the treatment plans more. This is illustrated again by P13 experiences. She understood that the data from her wearable were not useful for guiding her providers’ practices (the one who did the IVF) in comparison to the data generated from clinical tests: “*I showed him the graph [fertility graph from the wearable device] once because he was interested to see it, but he kind of just glanced at it. He didn’t analyze anything that it had said since I was going for blood draws every 48 hours. The blood draws are obviously the most accurate to determine your levels of everything.*”

Providers can also help patients engage with their own self-tracked data differently. For instance, D2 described trying to help patients that track too much data to figure out what are the best data to use depending on “*what you are using that for,*” such as when patients use multiple types of data to predict ovulation: “*and then when you have multiple ways of tracking, it’s also possible for us to help them by looking at which of those ways is best [...] in helping you to predict ovulation.*” Similarly, D3 commented they do not analyze their patients’ self-tracked data in detail, but use the data to educate their patients: “*I look at it [data], I see if it’s reasonable and then I tell them, ‘okay, now based on this app, do you know why it’s telling you to have sex during this day, at this time?’ And a lot of them, most of them can explain to me why but if not, I say, ‘it’s not day 14 for everyone,’ and explain the physiology behind that. [...] And I think a lot of patients don’t know that, so I make sure that their app is coinciding with that*” [D3].

We even found that these well-explained rationales of using data can influence patients’ own data practices outside of the clinical encounters, when patients apply what they learned from providers instead of tracking reactively or obsessively: “*I liked having the information [self-tracked data from the wearable]. Pretty much did everything the doctor said. I got my OPKs and everything through him and did all the blood draws and looked through that information [self-tracked data]. I kept track of my numbers myself just because I’m interested in that stuff. But, at a certain point I kind of let the doctors take over keeping track of everything*” [P13]. Patients appreciate this use of their data, since it can help guide them not only through the protocol, but also through the sea of fertility information available for consumption, as described by P11: “*There’s still so much we don’t know about what causes fertility. But I feel like she [midwife] did a good job of helping me deal with ambiguous information and with the unknowns while giving me information that was more concrete, you know what I mean, about the things that I can do.*” Such practices also foreground how much is known about fertility, which helps in avoiding creating expectations that cannot be met and supports patients in building the structure and plan they need.

In summary, when providers do not explain their rationale of data use and decision-making process, patients get confused and may not trust their decisions. Because patients in general do not understand the data practices engaged by the providers (what types of data they value and why), they may misunderstand providers for not taking their personal data and experiences seriously. However, when providers make their rationale and data practices clear, patients often comply to their decisions and, sometimes, even change their own practices using data in a more balanced way.

#### 5.4.2 Considering and Addressing Patients’ Emotional and Personalized Needs.

Since providers and patients engage in very different data practices, when providers encounter patients’ trajectories, they may not always understand the concerns, preferences, and personal situations patients encounter. The REIs we interviewed acknowledged that patients’ data practices are a “*powerful way for us to feel like we’re taking control of our life, and we don’t feel powerless*”

[D4]. However, as we mentioned earlier, these data may not be directly related to providers' decision-making process and thus may not be used.

Although patients have various experiences with providers not checking their data, the REIs we interviewed all mentioned they try their best to look at patients' data, even just skim through them to get the information they need. However, their use of patients' tracking data is different from their use of clinical data. They do not try to use all patients' data for the purposes of diagnosis or treatment, but use it to understand and validate patients' experiences. If patients bring extensive data, these REIs try to reassure patients' practices. If the patient is obsessing, they try to validate their feelings and suggest mental health support, as described by D4: *"If they come with a big Excel [...] I try to positively affirm them and then talk with them about what all this means. A lot of what we do is reassurance that this is occurring. And then I talk with them about healthy lifestyle choices, healthy mental habits to protect their mental health. Because when we fixate on things like that, sometimes people spiral into a depression or an anxiety that's really hard to get out of. So, a lot of it is reassurance that, 'this is normal. This is happening. Thank you so much for bringing me this information.'"* As D4 indicated, since REIs work almost exclusively with fertility issues, they have a deeper understanding about patients' data and the emotional struggles they may face. The data brought in by patients thus serve as a basis for them to understand patients' past trajectories.

By reassuring patients' data practices and normalizing their experiences, D4 indirectly addressed the larger emotional context involved in patients' fertility trajectories. D4 also commented they start the first appointment asking patients to describe their goals so they can personalize the treatment: *"I like to start the visit asking them to tell me – in their own words – what brings them in today, what their thoughts are, and what their goals are. [...] I always like to ask my couples – in relation to their overall goals – how many children in an ideal world they would want. Because my recommendations depending on the woman's age, may be very different if she wants one child vs. if she wants two, three, or four children as a couple, together."* By understanding what caused patients' extensive (and potentially obsessive) data tracking behaviors, providers can then suggest ways to support their mental health, direct them to other forms of support, and provide enough structure and the most clear and objective information so there will be less room for patients feeling out of control: *"We talk with patients about finding whatever it is that helps relieve stress for them, so whether that's mild exercise, meditation, yoga, spending time with family – we try to help them focus on those things too. And then also, just trying to make things as clear as possible so that things go according to plan and patients aren't meeting a lot of unexpected challenges, because I think that adds more stress"* [D1].

Fertility treatments protocols are often based on a general "illness" trajectory that generalizes from a larger population. However, like described before, fertility is still unknown, and patients' personal fertility trajectories vary significantly. Patients' data and their emotional involvement with these data, can also support providers in learning more about patients' trajectories. It does not necessarily mean providers need to examine in detail extensive tracked data: patients can talk through their data to answer providers' questions. This process could help providers in identifying exceptions to their protocol. For example, P1 described reporting to five different healthcare providers how her periods were painful, and how she thought this might relate to her fertility challenges. She explained that, because she was young (25 years old) and always had regular periods, these providers seemed to not pay attention to her experiences: *"all of them would ask me questions while they were examining or right beforehand. But it was 'hurum-hurum.' It's more like kind of lightly mentally checklist."* After 5 years, she finally found a provider who asked her *"detailed questions about specific pain, areas, and how frequently, and how many tablespoons [blood flow] during a regular period"* which led, alongside specific tests, to a diagnosis of endometriosis. Following the general "illness" protocol, it is less likely that young people with regular periods will not have fertility issues [73,94]. However, the average age of our participants when they first faced fertility challenges is 29, and four of them (P1, P4, P6, P8) explicitly mentioned they always had regular periods. These examples suggest that engaging more with

patients' specific data may be helpful to recognize their individual struggles that do not follow the standard decision rationale.

P11 provided a good example on how patients and providers different data practices can work together. She explained that, although her midwife would not deeply analyze her data, she would listen to her descriptions and consider her information: *"when we did Clomid, I think the first dose I didn't really ovulate. And so then, I was showing her the [temperature] chart or I was describing the data I was collecting [temperature, OPK, cervical mucus, cervical position, and symptoms] to her, and she increased the dose. So, it was that kinda thing. It's not like we were sitting at my computer looking at stuff together. I think I took my laptop to the office a couple times. She'd be like, 'oh okay. Well, just tell me what does it say.' [P11]. In this case, the patient talked through her data to the provider, who identified that the patient needed an increased dose of medication to ovulate.*

In summary, although patients detailed data practices are often not useful for the decision making process, to some extent engaging with patients' data and practices can be useful to understand their trajectories, recognize possible exceptions, address their emotional state, and provide the support and structure that help them reduce the feeling of being out of control.

## 6 DISCUSSION

As our findings show, individuals facing fertility challenges often build expectations and data practices before contacting healthcare providers. Strauss et al. [82] argue that technology can produce new trajectories, which can bring new challenges to both health providers and patients. Technologies related to data can play a role in how patients react or participate in health work [82]. Our findings show that patients' data practices are entangled with their fertility trajectories and affect their interactions with providers. Leveraging Strauss et al. [82] discussion, understanding how data play a role in patients' fertility trajectories is necessary to understand their illness management practices and how to better support them, especially when self-tracking data has become increasingly present in today's clinical encounters.

Based on our findings, we first examine the characteristics of the uncertainties faced by (in)fertility patients and how their data practices emerge in this context. Then we discuss the reasoning behind the two different data practices (i.e., the different ways patients and providers value and use PGHD). Finally, we suggest that instead of trying to completely merge patients' data into providers' practices, technology should bridge patient and provider's data practices supporting their independent coexistence and necessary interactions.

### 6.1 "The Unknown:" Uncertainty in Fertility Struggles.

Facing any health condition is a disruptive event largely because of the uncertainties it creates. Uncertainty has been considered a central aspect of both chronic and acute illness experiences [8,11]. It is inherently related to the difficulties in understanding illness' events, particularly regarding the effects on daily life, symptoms, treatment paths, unpredictable outcomes, and how the future will unfold [8,11,63]. Uncertainty has been reported as a major source of distress for patients with different health conditions during their illness trajectories [11] such as cancer [80], stroke [8], HIV [11], and bone marrow transplant [12].

Similar to these health conditions, patients facing (in)fertility challenges also have to deal with the distress caused by uncertainties, which many of our participants referred to as "the unknown." However, infertility presents unique challenges to approach this unknown. First there is still fairly limited scientific knowledge about fertility: there are numerous potential factors, entangled with complex hormonal changes in the body, that influence people's fertility cycles and are not completely understood [81]. Besides, different from other diseases where people expect to be back to normal or control their symptoms, infertility does not present any symptom or directly impact

people's health conditions [35]. Instead, it relates to their goal for the future, such as their life plans, and the biography they imagined for themselves [18,75].

Individuals' relationships with personal data are also different. In conditions such as diabetes, individuals can see how their data (e.g., glucose levels) are connected to the condition and its progress. In contrast, people facing fertility challenges often do not even know which and how much data are relevant to their goal, since many factors can influence fertility and they change from person to person [20,21]. These challenges add uncertainty to an already uncertain context. Therefore, individuals' struggles with infertility are directly and repeatedly influenced by the "unknown." As discussed in previous studies [21], reflection on data [53] and sensemaking [59] become much more complex in such context.

Finally, unlike in many other health conditions, in fertility individuals are expected to directly influence and impact the outcomes of their fertility trajectories through personal actions. For example, cancer patients face similar intense uncertainties in their trajectories: it is unexpected, personalized, not fully scientifically understood, and the cure (most common goal) may not be easily achieved. However, most cancer treatments are performed by healthcare professionals within the healthcare system. Patients can support and participate in their care through self-management activities [40]. They are expected to support and follow healthcare providers guidance, but their personal actions may not alter or impact their treatment results. In comparison, in the fertility context, the data practices are seen as directly contributing to individuals' end goal which increases the pressure for persistent action [20,51]. This is also aligned with societal pressures and gender stereotypes entangled with fertility [20,55], which increase the emotional involvement and the consequent entanglement of emotions and data practices [20]. Finally, all the data work is done under time pressure: all self-tracking activities need to be performed within each cycle, often with the threatening feeling that time is passing by, reducing the biological chances of conception. These complexities associated with fertility data practices add to individuals' "patient work" [18] increasing the complexity of their trajectories [82] of fertility experiences.

## 6.2 The Different Data Practices: Emotions vs Rationality.

Our findings show both patients and providers use data to explore "the unknown", but this exploration has different characteristics. As summarized in Table 2, patients' data practices are much more exploratory, embedded in their lived experiences and driven by their emotions, while providers' data practices are more objective, supported by the rationality commonly applied in medical decision-making. These differences highlight how fertility trajectories are entangled with the tensions between "*the voice of medicine*" and patients lived experiences [35].

Medicine has a long history of emphasizing rationality to support more objective practices and reduce the uncertainty [9] that leads to "the unknown" described by our participants. Providers' data practices are rooted in this tradition and are based on medical research, scientific evidence, and their own expertise and experiences practicing medicine through the years [9,84]. Healthcare providers use PGHD and the results of clinical tests to visualize "*the illness course and some of its attendant medical work*" [18] (p.238) following a protocol that resembles a decision tree: the data points they need are used to answer questions, eliminate possible infertility causes, and guide their decision-making process until they define the best treatment course. This protocol is based on probabilities and statistics of a typical illness trajectory and prioritizes certain types of data that are considered more reliable and often more objective (e.g., OPKs and laboratory tests) to identify the best treatment path. Other data are often not considered useful in this decision-making process. However, as our findings suggest, such data practices may not account for patients' individual differences and experiences, particularly in a context that is highly personalized, highly uncertain, and still scientifically unknown. As our data demonstrate, patients commonly do not experience the typical illness trajectory inscribed in the decision tree. Besides, healthcare providers do not have the same emotional connection patients have with their data or know their lived experiences

in their fertility trajectories. They mostly work with data with rationality, while patients are living with data embedded in emotions.

Table 2. Differences between patients' and providers' data practices

Patient	Provider
A combination of multiple types of data	A few defined types of data
Often use subjective data	Use controlled, clinical data
Large quantity of data	Summarized data
Driven by emotions	Driven by medical rationality
Learning about the body	Using medical expertise
Trying different things	Following a protocol
Living with data	Working with data

Patients experience infertility in a much more emotional way, because their fertility trajectories are directly related to the life plan they envisioned for themselves and their data practices often directly disrupt their daily lives (e.g., tracking, analyzing data, having programmed intercourse) [7,18]. The experiences of infertility have been previously described as a “*roller coaster of raised hopes followed by tragic disappointment*” [34], an expression that was echoed by our participants. In order to persistently manage their trajectory, patients need to project a future and visualize ways to get there, which involves hope and commitment [18]. Data then becomes a way for patients to act towards their projected future, so they can feel like they have some control over the unknown. Patients' data practices are a mix of diagnostic, behavior change, and goal-oriented self-tracking [28,53,76]: they use varied data to try to identify possible causes of infertility (diagnostic), so they can change them (behavior change) and act towards their goal (goal-oriented). However, though such data practices help patients to learn about their bodies and fertility, they still cannot completely decipher the unknown, as many participants experienced in our study. Previous research analyzing fertility self-tracking through the sensemaking framework [21] has described that, because of the complexity of the condition and the challenges of self-tracking, individuals facing fertility struggles spend most of their time trying to make sense of their data [59]. Our study builds on these findings to explore how individuals use these data practices to deal with the uncertainty of their situation throughout their fertility trajectories, suggesting that in this context data work as an illusion of certainty [8]: patients' data practices aim to bring objectivity to their experiences [67], but patients' trajectories are so emotionally embedded in their lives that having access to extensive data does not make their experiences less challenging [45]. Furthermore, as described by previous studies [20], when people do not receive desirable results, these data practices can lead to stronger emotional consequences, and evolve to obsessive behaviors.

As our findings suggest, patients' and providers' data practices are not only different, they serve different purposes. The inherent differences suggest that to bridge the sides of practices, it is not as simple as merging self-tracked data into providers practices, or as rationalizing patients' data practices to fit providers' protocol. There are unique benefits in each form of data practices, and they should be approached cautiously. On the one hand, although providers' data practices can overlook important aspect of patients' idiosyncratic trajectories, they are useful to define the best, most viable, and affordable treatment course, investigating aspects of the body that patients are not able to access by themselves. It is not feasible to expect providers to analyze months of self-tracked fertility data, which could potentially delay treatment; and time is an important factor in the fertility context. Also, providers' protocol is based on current medical knowledge, which aims to benefit majority of cases [84]. Imposing high levels of personalization may impact cases that would be easily supported by the current protocol. On the other hand, although patients' data practices do not lead them to understand the unknown, they help them in learning about their bodies, which is beneficial not only for them, but for providers as well. Patients' data practices also serve as a way

to make them feel that they are in control and empowered amidst the uncertainty and unknown in their fertility trajectories. These feelings give patients the structure they need to cope with the disruptive experience of infertility. Although applying the rationality used in providers' data practices to patients' data practices may be useful, aiming to completely change patients' practices to mimic providers' protocol could hinder the benefits related to their coping mechanisms and feelings of agency. It would also hide the personalized aspects of their trajectory that can point to exceptions to the protocol. Similar to previous analysis of infertility treatments and experiences [34], focusing on adjusting patients' data practices solely to fit providers' protocol can shift our attention from how to adjust infertility treatments for better supporting people to how people facing fertility challenges should be adjusted to fit processes that may be "*imperfect*" to their reality.

### 6.3 Bridging Different Data Practices.

The differences between patients' and providers' data practices may lead to confusion, misunderstanding, and mistrust when they interact during the treatment period, which add to and become entangled with the traditional challenges of a fertility treatment process (e.g., tests' accuracy, treatment results, or healthcare provider communication styles). Previous PGHD studies suggest changing patients' data practices to fit providers' practices (e.g., collecting only the data providers value in the moments they value, or encouraging provider-initiated tracking) [41,90]. However, as our study shows, this practice may not work for the highly uncertain and unknown nature of fertility because it could reduce or even hinder the benefits of patients' own data practices. It is also often not possible because patients often engage in their own data practices before a provider works more closely with them. Other studies suggest technologies to facilitate providers' analysis of patients' data, such as providing more data and metadata to enhance reliability [77,90], supporting data analysis before appointments [87], supporting collaborative review of data with patients [46,62,79], or promoting integrating PGHD with clinical practices and systems [46,48,77,90]. While these are valuable approaches, what we found in this study is that it is also crucial to consider the principles that guide the differences in patients' and providers' data practices, because in some cases it may be more indicated to connect their data practices without merging patients' data into providers' practices and systems.

As explained in the previous section, there are different considerations guiding these data usages. PGHD carry different meanings to providers and patients and are used differently with different consequences, which suggests there exists a boundary between their practices. As our findings suggest, data do not pass directly through this boundary. It often requires negotiation and adaptation from both sides. Instead of trying to make this boundary invisible by merging patients' data into providers' practices, our findings suggest that it may be more useful to make the boundary more visible to the different users so patients can understand providers' protocol clearly and providers' can learn patients' fertility trajectories better [10]. Therefore, this study suggests instead of merging, bridging the two data practices: support their independent coexistence and the eventual connections necessary to feed and balance each other. If the boundary between their practices is visible, collaboration through PGHD can be easier and each group can maintain their own practices but also consider the other side of the boundary to further benefit their data usages and collaboration [10]. Patients' data can be used to feed providers' protocol in the specific moments when they need them. Patients' data can also bring the emotions they experience to provider's practices. Reversely, providers' data practices can introduce their expert knowledge and rationality into patients' trajectory, supporting them in interpreting their data, and providing the structure they need to balance their sense of control. The bridge between their different data practices can support patients and providers to collaborate through the boundary to explore the unknown in the specific context of patients' fertility trajectories. This bridge suggests the need of boundary negotiation artifacts [17,50] that can communicate both trajectory experiences and decision-making reasoning across the boundary. Boundary negotiation artifacts are artifacts and practices used to coordinate different

perspectives, align different groups of users, and facilitate crossing and pushing boundaries [17,50]. Such objects highlight the existence of a boundary that separates different spheres of expertise and requires different types of data for different purposes. Based on our findings, we suggest that fertility technologies can be designed to bridge this gap in the following ways:

*Making providers' data practices transparent.* Our findings suggest that many conflicts between patients and providers result from the lack of transparency in providers' data practices. Chung et al. [17] argue that patient instructions are a form of boundary negotiation compilation artifacts created by providers. Our findings suggest that such artifacts should include explanations of providers' reasoning and how PGHD fits in this process (e.g., what data and tests they need and how their results take them to the treatment). Making the rationale transparent to patients can help them understand providers' decision-making process and how it is supported by data. If patients understand the protocol providers use to define treatments and its underlying reasoning, they can be prepared to provide the necessary data to support them. In addition, making providers' data practices accessible to patients may help reduce the uncertainty for patients [8,63] and influence their own engagement with data, proposing a more rationalized data use without limiting the benefits of their existing data practices. Technology can potentially support this by showcasing providers protocol (maybe even using the decision tree analogy) alongside the fertility information important for conceiving. So, when patients learn about their bodies, they may also learn how providers approach fertility challenges. For supporting the moments in which the practices interact, technology can provide summarized information that can support providers in gathering the data they want without hindering patients own data practices activities (D1 liked apps' calendar feature for this reason), and artifacts that can help providers in describing to patients their reasoning and how the proposed treatment is connected to the data, either tracked or clinical. Future work is needed to explore how fertility data should be collected and owned by these different stakeholders in order to support bridging their practices and preserve users' privacy, particularly considering current concerns related to private companies' ownership of these data [32,91].

*Considering different trajectories.* Kaziunas et al. [45] argue that "*there are many unexpected and deeply human narratives about data still emerging and that these stories offer an alternative way of living with data.*" In our study, patients engaged with data in varied ways in their unique fertility trajectories. Instead of trying to make patients' data practices mimic providers' and turn to be completely rationalized, summarized, and objective, it is also important for PGHD to carry the uniqueness of each patient's trajectory. For example, patients described good interactions when providers let them talk through their data. Although such verbal descriptions of data can be considered boundary negotiation inclusion artifacts (which bring information from one side of the boundary to the other) [17], such communication may not always be well structured and spontaneous. Our findings call for more structured artifacts that can facilitate both patients' and providers' practices and support patients to articulate the important details of their trajectory. Technology could support such interactions, allowing patients to share certain aspects of their experiences that may be useful for providers to understand the individualized challenges they faced in the past without omitting important details. Past research on rare diseases have suggested the use of summaries of patients' conditions to clinicians that do not have disease-related expertise [39,57]. Fertility technology could draw from such suggestions to support patients in providing an overview of their trajectory, including information on treatments they have tried, specialties of healthcare providers they previously worked with, fertility-related events they experienced, relationship with tracking (what, how, and how often they track), and treatment goals. Such summaries could also include information on patients' values important to care, such as how many children the person would like to have or strong preferences for trying naturally and avoiding IVF.

*Addressing the emotional involvement with data.* Fertility is strongly connected with emotions. Providers are not able to ease the complex emotional context involved in patients' trajectories and its relationship with data [20]. However, the existence of such relationship impacts their practices. Addressing patients' emotional needs is as critical for improving care as it is to treat their physical

needs [66]. Providing reassurance, as described by our REI interviewees, is a subtle way to address the complex emotional context around fertility and a good way to normalize patients' experiences: previous studies have described reassurance alleviates feelings of guilt and helps tackling stigma related to infertility [70]. In this context, technology could support patients by including mental health related practices and not only tracking the body. Research in cancer care have suggested tracking emotional health to support providers in recognizing patients' emotional needs [41], while a previous study of multiple sclerosis suggested the use of journaling as way to support mindful disease monitoring [4]. Every patient's experience is different and because of the taboos related to fertility, emotions can be hidden and not shared. As such, having the emotional experience documented in a PGHD system that supports meaningful sharing with providers would allow providers to have indications of the real lived experiences of patients. It can support them in providing assistance to address patients' emotional needs and it may even help them understand the underlying causes that account for such emotions or recognize patterns of negative experiences.

*Exposing how much is known.* Although there have been important scientific developments in recent years, fertility is still uncertain: the unknown is unknown. It is important to showcase uncertainty to avoid reinforcing unrealistic expectations. Previous studies have discussed [20] and explored [78] how to communicate uncertainty in fertility data and predictions to patients. However, fertility is also uncertain to healthcare providers. Understanding the uncertainty could help in avoiding patients viewing treatments as cures, which would make it easier to accept that treatments may not work as expected. Similar features proposed by previous fertility studies focusing on uncertainty in patients data practices [20,78] could be used to communicate to patients the uncertainty existing in providers' data practices and support them in learning the nature, limitation, and different usages of data.

## 8 CONCLUSIONS

Medical practices have always been data oriented. With the rise of PGHD other types of data are entering these practices and influencing patient-provider collaboration. We studied the use of PGHD and related data practices in the context of an uncertain, complex, and data-intensive health concern: fertility with the goal of conception. Our findings show that patients and providers use PGHD differently but with the common goal of exploring "the unknown." Providers use patients' data in a rational protocol, aiming to identify infertility causes and define a treatment course. Patients use data in a much more emotional way, learning about their bodies while struggling with challenges in data interpretation. We discuss that both these practices have benefits for their specific groups and that the principles that drive them should be considered and supported when developing fertility technologies. Finally, we suggest that fertility technologies should aim to make the boundary between patients' and providers' data practices more visible so their practices can be bridged, facilitating collaboration when necessary and also maintaining their independent benefits.

## ACKNOWLEDGEMENTS

We gratefully thank all our participants who confided us their intimate fertility experiences and the many individuals who helped our recruitment efforts. This work was partially supported by the UCI Donald Bren School of Information and Computer Sciences Exploration Award.

## REFERENCES

1. Teresa Almeida, Rob Comber, and Madeline Balaam. 2016. HCI and Intimate Care As an Agenda for Change in Women's Health. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), 2599–2611. <https://doi.org/10.1145/2858036.2858187>
2. Jessica S. Ancker, Holly O. Witteman, Baria Hafeez, Thierry Provencher, Mary Van de Graaf, and Esther Wei. 2015. "You Get Reminded You're a Sick Person": Personal Data Tracking and Patients With Multiple Chronic Conditions. *Journal of Medical Internet Research* 17, 8: e202. <https://doi.org/10.2196/jmir.4209>

3. Nazanin Andalibi and Andrea Forte. 2018. Announcing Pregnancy Loss on Facebook: A Decision-Making Framework for Stigmatized Disclosures on Identified Social Network Sites. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI '18), 158:1–158:14. <https://doi.org/10.1145/3173574.3173732>
4. Amid Ayobi, Paul Marshall, Anna L. Cox, and Yunan Chen. 2017. Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), 6889–6901. <https://doi.org/10.1145/3025453.3025869>
5. Madeline Balaam, Rob Comber, Ed Jenkins, Selina Sutton, and Andrew Garbett. 2015. FeedFinder: A Location-Mapping Mobile Application for Breastfeeding Women. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (CHI '15), 1709–1718. <https://doi.org/10.1145/2702123.2702328>
6. Stinne Aaløkke Ballegaard, Thomas Riisgaard Hansen, and Morten Kyng. 2008. Healthcare in Everyday Life: Designing Healthcare Services for Daily Life. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '08), 1807–1816. <https://doi.org/10.1145/1357054.1357336>
7. Gay Becker. 1994. Metaphors in Disrupted Lives: Infertility and Cultural Constructions of Continuity. *Medical Anthropology Quarterly* 8, 4: 383–410. <https://doi.org/10.1525/maq.1994.8.4.02a00040>
8. Gay Becker and Sharon R. Kaufman. 1995. Managing an uncertain illness trajectory in old age: patients' and physicians' views of stroke. *Medical anthropology quarterly* 9, 2: 165–187.
9. Marc Berg and Principal Advisory Marc Berg. 1997. *Rationalizing medical work: decision-support techniques and medical practices*. MIT press.
10. Susanne Bødker. 2016. Rethinking technology on the boundaries of life and work. *Personal and Ubiquitous Computing* 20, 4: 533–544.
11. Dale E. Brashers, Judith L. Neidig, Nancy R. Reynolds, and Stephen M. Haas. 1998. Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care* 9, 1: 66–77.
12. Ayşe G. Büyüktür and Mark S. Ackerman. 2017. Information work in bone marrow transplant: Reducing misalignment of perspectives. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*, 1740–1752.
13. Alessandro Cavaliere, Santina Ermito, Angela Dinatale, and Rosa Pedata. 2009. Management of molar pregnancy. *Journal of Prenatal Medicine* 3, 1: 15–17.
14. CDC. 2016. FastStats - Infertility. Retrieved April 13, 2018 from <https://www.cdc.gov/nchs/fastats/infertility.htm>
15. Kathy Charmaz and Liska Belgrave. 2012. Qualitative interviewing and grounded theory analysis. *The SAGE handbook of interview research: The complexity of the craft* 2: 347–365.
16. Eun Kyoung Choe, Nicole B. Lee, Bongshin Lee, Wanda Pratt, and Julie A. Kientz. 2014. Understanding Quantified-selfers' Practices in Collecting and Exploring Personal Data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '14), 1143–1152. <https://doi.org/10.1145/2556288.2557372>
17. Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing* (CSCW '16), 770–786. <https://doi.org/10.1145/2818048.2819926>
18. Juliet Corbin and Anselm Strauss. 1985. Managing chronic illness at home: three lines of work. *Qualitative sociology* 8, 3: 224–247.
19. Felícia Cordeiro, Daniel A. Epstein, Edison Thomaz, Elizabeth Bales, Arvind K. Jagannathan, Gregory D. Abowd, and James Fogarty. 2015. Barriers and Negative Nudges: Exploring Challenges in Food Journaling. *Proceedings of the SIGCHI conference on human factors in computing systems CHI Conference 2015*: 1159–1162. <https://doi.org/10.1145/2702123.2702155>
20. Mayara Costa Figueiredo, Clara Caldeira, Elizabeth V. Eikey, Melissa Mazmanian, and Yunan Chen. 2018. Engaging with Health Data: The Interplay Between Self-Tracking Activities and Emotions in Fertility Struggles. In *Proc. ACM Hum.-Comput. Interact.* <https://doi.org/10.1145/3274309>
21. Mayara Costa Figueiredo, Clara Caldeira, Tera L. Reynolds, Sean Victory, Kai Zheng, and Yunan Chen. 2017. Self-Tracking for Fertility Care: Collaborative Support for a Highly Personalized Problem. *Proc. ACM Hum.-Comput. Interact.* 1, CSCW: 36:1–36:21. <https://doi.org/10.1145/3134671>
22. Pooja M. Desai, Elliot G. Mitchell, Maria L. Hwang, Matthew E. Levine, David J. Albers, and Lena Mamykina. 2019. Personal Health Oracle: Explorations of Personalized Predictions in Diabetes Self-Management. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (CHI '19), 1–13. <https://doi.org/10.1145/3290605.3300600>
23. Catherine D'Ignazio, Alexis Hope, Becky Michelson, Robyn Churchill, and Ethan Zuckerman. 2016. A Feminist HCI Approach to Designing Postpartum Technologies: “When I First Saw a Breast Pump I was Wondering if It Was a Joke.” In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems* (CHI '16), 2612–2622. <https://doi.org/10.1145/2858036.2858460>
24. Xianghua Ding, Yunan Chen, Zhaofei Ding, and Yiwen Xu. 2019. Boundary Negotiation for Patient-Provider Communication via WeChat in China. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW: 1–24.
25. Elizabeth V. Eikey and Madhu C. Reddy. 2017. “It’s Definitely Been a Journey”: A Qualitative Study on How Women with Eating Disorders Use Weight Loss Apps. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17), 642–654. <https://doi.org/10.1145/3025453.3025591>
26. Jane Elliott. 2005. Listening to people’s stories: The use of narrative in qualitative interviews. *Using narrative in social research*: 17–35.

27. Daniel A. Epstein, Nicole B. Lee, Jennifer H. Kang, Elena Agapie, Jessica Schroeder, Laura R. Pina, James Fogarty, Julie A. Kientz, and Sean Munson. 2017. Examining Menstrual Tracking to Inform the Design of Personal Informatics Tools. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, 6876–6888. <https://doi.org/10.1145/3025453.3025635>
28. Daniel A. Epstein, An Ping, James Fogarty, and Sean A. Munson. 2015. A Lived Informatics Model of Personal Informatics. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '15)*, 731–742. <https://doi.org/10.1145/2750858.2804250>
29. Sergio Felipe, Aneasha Singh, Caroline Bradley, Amanda CdeC Williams, and Nadia Bianchi-Berthouze. 2015. Roles for Personal Informatics in Chronic Pain. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '15)*, 161–168. Retrieved October 4, 2018 from <http://dl.acm.org/citation.cfm?id=2826165.2826189>
30. Mayara Costa Figueiredo and Yunan Chen. 2020. Patient-Generated Health Data: Dimensions, Challenges, and Open Questions. *Foundations and Trends® in Human-Computer Interaction* 13, 3: 165–297.
31. Margaret Flemings, Shanzay Kazmi, Rachel Pak, and Orit Shaer. 2018. Crimston Wave: Shedding Light on Menstrual Health. In *Proceedings of the Twelfth International Conference on Tangible, Embedded, and Embodied Interaction (TEI '18)*, 343–348. <https://doi.org/10.1145/3173225.3173292>
32. Sarah Fox, Noura Howell, Richmond Wong, and Franchesca Spektor. 2019. Vivewell: Speculating Near-Future Menstrual Tracking Through Current Data Practices. In *Proceedings of the 2019 on Designing Interactive Systems Conference (DIS '19)*, 541–552. <https://doi.org/10.1145/3322276.3323695>
33. Frost & Sullivan. 2018. Femtech—Time for a Digital Revolution in the Women’s Health Market. *Frost & Sullivan*. Retrieved September 7, 2019 from <https://www2.frost.com/frost-perspectives/femtechtime-digital-revolution-womens-health-market/>
34. Arthur L. Greil. 1997. Infertility and psychological distress: A critical review of the literature. *Social Science & Medicine* 45, 11: 1679–1704. [https://doi.org/10.1016/S0277-9536\(97\)00102-0](https://doi.org/10.1016/S0277-9536(97)00102-0)
35. Arthur L. Greil, Kathleen Slauson-Blevins, and Julia McQuillan. 2010. The experience of infertility: a review of recent literature. *Sociology of Health & Illness* 32, 1: 140–162. <https://doi.org/10.1111/j.1467-9566.2009.01213.x>
36. Erik Grönvall and Nervo Verdezoto. 2013a. Beyond Self-monitoring: Understanding Non-functional Aspects of Home-based Healthcare Technology. In *Proceedings of the 2013 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '13)*, 587–596. <https://doi.org/10.1145/2493432.2493495>
37. Xinning Gui, Yu Chen, Yubo Kou, Katie Pine, and Yunan Chen. 2017. Investigating Support Seeking from Peers for Pregnancy in Online Health Communities. *Proc. ACM Hum.-Comput. Interact.* 1, CSCW: 50:1–50:19. <https://doi.org/10.1145/3134685>
38. Sarah Homewood, Laurens Boer, and Anna Vallgård. 2020. Designers in White Coats: Deploying Ovum, a Fertility Tracking Device. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–13.
39. Maia Jacobs, Galina Gheihman, Krzysztof Z. Gajos, and Anoopam S. Gupta. 2019. “I think we know more than our doctors” How Primary Caregivers Manage Care Teams with Limited Disease-related Expertise. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW: 1–22.
40. Maia Jacobs, Jeremy Johnson, and Elizabeth D Mynatt. 2018. MyPath: Investigating breast cancer patients’ use of personalized health information. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW: 1–21.
41. Maia L. Jacobs, James Clawson, and Elizabeth D. Mynatt. 2015. Comparing Health Information Sharing Preferences of Cancer Patients, Doctors, and Navigators. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*, 808–818. <https://doi.org/10.1145/2675133.2675252>
42. Sandra Jovchelovitch and Martin W. Bauer. 2000. Narrative interviewing. *Qualitative researching with text, image and sound: 57–74*.
43. Ravi Karkar, Jessica Schroeder, Daniel A. Epstein, Laura R. Pina, Jeffrey Scofield, James Fogarty, Julie A. Kientz, Sean A. Munson, Roger Vilardaga, and Jasmine Zia. 2017. TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*, 6850–6863. <https://doi.org/10.1145/3025453.3025480>
44. Dmitri Katz, Blaine Price, Simon Holland, and Nick Dalton. 2018. Data, Data Everywhere, and Still Too Hard to Link: Insights from User Interactions with Diabetes Apps. Retrieved April 2, 2018 from <http://nrl.northumbria.ac.uk/33422/>
45. Elizabeth Kazianas, Mark S. Ackerman, Silvia Lindtner, and Joyce M. Lee. 2017. Caring through Data: Attending to the Social and Emotional Experiences of Health Datafication. 2260–2272. <https://doi.org/10.1145/2998181.2998303>
46. Yoojung Kim, Eunyoung Heo, Hyunjeong Lee, Sookyong Ji, Jueun Choi, Jeong-Whun Kim, Joongseek Lee, and Sooyoung Yoo. 2017. Prescribing 10,000 steps like aspirin: designing a novel interface for data-driven medical consultations. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 5787–5799.
47. Jennifer L. Kraschnewski, Cynthia H. Chuang, Erika S. Poole, Tamara Peyton, Ian Blubaugh, Jaimey Pauli, Alyssa Feher, and Madhu Reddy. 2014. Paging “Dr. Google”: does technology fill the gap created by the prenatal care visit structure? Qualitative focus group study with pregnant women. *Journal of Medical Internet Research* 16, 6: e147. <https://doi.org/10.2196/jmir.3385>
48. Rajiv B. Kumar, Nira D. Goren, David E. Stark, Dennis P. Wall, and Christopher A. Longhurst. 2016. Automated integration of continuous glucose monitor data in the electronic health record using consumer technology. *Journal of the American Medical Informatics Association: JAMIA* 23, 3: 532–537. <https://doi.org/10.1093/jamia/ocv206>

49. Amanda Lazar, Norman Makoto Su, Jeffrey Bardzell, and Shaowen Bardzell. 2019. Parting the Red Sea: Sociotechnical Systems and Lived Experiences of Menopause. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (CHI '19), 480:1–480:16. <https://doi.org/10.1145/3290605.3300710>
50. Charlotte P. Lee. 2007. Boundary negotiating artifacts: Unbinding the routine of boundary objects and embracing chaos in collaborative work. *Computer Supported Cooperative Work (CSCW)* 16, 3: 307–339.
51. Mihan Lee. 2017. Don't Give Up! A Cyber-ethnography and Discourse Analysis of an Online Infertility Patient Forum. *Culture, Medicine, and Psychiatry* 41, 3: 341–367. <https://doi.org/10.1007/s11013-016-9515-6>
52. Tzu-I Lee, Yih-Harn Chiang, Jiayi Guo, Mu-Tsz Chen, and Yue Chen. 2016. Dot-it: Managing Nausea and Vomiting for A Peaceful Pregnancy with Personal Pattern Exploration. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems* (CHI EA '16), 20–25. <https://doi.org/10.1145/2851581.2890631>
53. Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A Stage-based Model of Personal Informatics Systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '10), 557–566. <https://doi.org/10.1145/1753326.1753409>
54. J. R. Loos and E. J. Davidson. 2016. Wearable Health Monitors and Physician-Patient Communication: The Physician's Perspective. In *2016 49th Hawaii International Conference on System Sciences (HICSS)*, 3389–3399. <https://doi.org/10.1109/HICSS.2016.422>
55. Deborah Lupton. 2015. Quantified sex: a critical analysis of sexual and reproductive self-tracking using apps. *Culture, Health & Sexuality* 17, 4: 440–453. <https://doi.org/10.1080/13691058.2014.920528>
56. Deborah Lupton and Sarah Pedersen. 2016. An Australian survey of women's use of pregnancy and parenting apps. *Women and Birth: Journal of the Australian College of Midwives* 29, 4: 368–375. <https://doi.org/10.1016/j.wombi.2016.01.008>
57. Haley MacLeod, Kim Oakes, Danika Geisler, Kay Connelly, and Katie Siek. 2015. Rare World: Towards Technology for Rare Diseases. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (CHI '15), 1145–1154. <https://doi.org/10.1145/2702123.2702494>
58. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '08), 477–486. <https://doi.org/10.1145/1357054.1357131>
59. Lena Mamykina, Arlene M. Smaldone, and Suzanne R. Bakken. 2015. Adopting the sensemaking perspective for chronic disease self-management. *Journal of Biomedical Informatics* 56: 406–417. <https://doi.org/10.1016/j.jbi.2015.06.006>
60. Maya N. Mascarenhas, Seth R. Flaxman, Ties Boerma, Sheryl Vanderpoel, and Gretchen A. Stevens. 2012. National, Regional, and Global Trends in Infertility Prevalence Since 1990: A Systematic Analysis of 277 Health Surveys. *PLOS Medicine* 9, 12: e1001356. <https://doi.org/10.1371/journal.pmed.1001356>
61. Mollie McKillop, Lena Mamykina, and Noémie Elhadad. 2018. Designing in the Dark: Eliciting Self-tracking Dimensions for Understanding Enigmatic Disease. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI '18), 565:1–565:15. <https://doi.org/10.1145/3173574.3174139>
62. Helena M. Mentis, Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a view of self-tracking data in the clinical visit. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 5800–5812.
63. Merle H. Mishel. 1988. Uncertainty in illness. *Image: The Journal of Nursing Scholarship* 20, 4: 225–232.
64. Sonali R. Mishra, Predrag Klasnja, John MacDuffie Woodburn, Eric B. Hekler, Larsson Omborg, Michael Kellen, and Lara Mangravite. 2019. Supporting Coping with Parkinson's Disease Through Self Tracking. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (CHI '19), 1–16. <https://doi.org/10.1145/3290605.3300337>
65. Manideepa Mukherjee, Sana Ali Naqvi, Anushika Verma, Debarka Sengupta, and Aman Parnami. 2019. MenstruLoss: Sensor For Menstrual Blood Loss Monitoring. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol.* 3, 2: 58:1–58:21. <https://doi.org/10.1145/3328929>
66. Tara Mullaney, Helena Pettersson, Tufve Nyholm, and Erik Stolterman. 2012. Thinking beyond the cure: A case for human-centered design in cancer care. *International Journal of Design* 6, 3.
67. Gina Neff and Dawn Nafus. 2016. *Self-Tracking*. MIT Press.
68. Lucille ML Ong, Johanna CJM De Haes, Alaysia M. Hoos, and Frits B. Lammes. 1995. Doctor-patient communication: a review of the literature. *Social science & medicine* 40, 7: 903–918.
69. Sun Young Park and Yunan Chen. 2015. Individual and Social Recognition: Challenges and Opportunities in Migraine Management. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15)*, 1540–1551. <https://doi.org/10.1145/2675133.2675248>
70. Dilisha Patel, Ann Blandford, Mark Warner, Jill Shawe, and Judith Stephenson. 2019. "I feel like only half a man" Online Forums as a Resource for Finding a "New Normal" for Men Experiencing Fertility Issues. *Proceedings of the ACM on Human-Computer Interaction* 3, CSCW: 1–20.
71. Tamara Peyton, Erika Poole, Madhu Reddy, Jennifer Kraschnewski, and Cynthia Chuang. 2014. "Every Pregnancy is Different": Designing mHealth for the Pregnancy Ecology. In *Proceedings of the 2014 Conference on Designing Interactive Systems (DIS '14)*, 577–586. <https://doi.org/10.1145/2598510.2598572>
72. Katie Pine. 2012. Fragmentation and choreography: caring for a patient and a chart during childbirth. In *Proceedings of the ACM 2012 conference on Computer Supported Cooperative Work*, 887–896.

73. Alexander Quaas and Anuja Dokras. 2008. Diagnosis and treatment of unexplained infertility. *Reviews in obstetrics and gynecology* 1, 2: 69.
74. Shriti Raj, Mark W. Newman, Joyce M. Lee, and Mark S. Ackerman. 2017. Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities. *Proc. ACM Hum.-Comput. Interact.* 1, CSCW: 88:1–88:18. <https://doi.org/10.1145/3134723>
75. Gerhard Riemann and Fritz Schütze. 1991. Trajectory as a basic theoretical concept for analyzing suffering and disorderly social processes. *Social organization and social process. Essays in honor of Anselm Strauss*: 333–357.
76. John Rooksby, Mattias Rost, Alistair Morrison, and Matthew Chalmers Chalmers. 2014. Personal Tracking As Lived Informatics. In *Proceedings of the 32Nd Annual ACM Conference on Human Factors in Computing Systems (CHI '14)*, 1163–1172. <https://doi.org/10.1145/2556288.2557039>
77. Patrick Sanger, Andrea Hartzler, Ross J. Lordon, Cheryl Al Armstrong, William B. Lober, Heather L. Evans, and Wanda Pratt. 2016. A patient-centered system in a provider-centered world: challenges of incorporating post-discharge wound data into practice. *Journal of the American Medical Informatics Association: JAMIA* 23, 3: 514–525. <https://doi.org/10.1093/jamia/ocv183>
78. Hanna Schneider, Julia Wayrauther, Mariam Hassib, and Andreas Butz. 2019. Communicating Uncertainty in Fertility Prognosis. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19)*, 161:1–161:11. <https://doi.org/10.1145/3290605.3300391>
79. Jessica Schroeder, Jane Hoffswell, Chia-Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals. *CSCW: proceedings of the Conference on Computer-Supported Cooperative Work. Conference on Computer-Supported Cooperative Work 2017*: 1726–1739. <https://doi.org/10.1145/2998181.2998276>
80. Maya Shaha, Carol L Cox, Kirsi Talman, and Daniel Kelly. 2008. Uncertainty in breast, prostate, and colorectal cancer: implications for supportive care. *Journal of Nursing Scholarship* 40, 1: 60–67.
81. Leon Speroff and Marc A. Fritz. 2005. *Clinical Gynecologic Endocrinology and Infertility*. Lippincott Williams & Wilkins.
82. Anselm Strauss, Shizuko Fagerhaugh, Barbara Suczek, and Carolyn Wiener. 1985. *Social organization of medical work*. University of Chicago Press, Chicago, IL, US.
83. Richard L. Street Jr, Lin Liu, Neil J. Farber, Yunan Chen, Alan Calvitti, Danielle Zuest, Mark T. Gabuzda, Kristin Bell, Barbara Gray, and Steven Rick. 2014. Provider interaction with the electronic health record: the effects on patient-centered communication in medical encounters. *Patient education and counseling* 96, 3: 315–319.
84. Stefan Timmermans and Rene Almeling. 2009. Objectification, standardization, and commodification in health care: a conceptual readjustment. *Social Science & Medicine (1982)* 69, 1: 21–27. <https://doi.org/10.1016/j.socscimed.2009.04.020>
85. Anupriya Tuli, Shaan Chopra, Neha Kumar, and Pushpendra Singh. 2018. Learning from and with Menstrupedia: Towards Menstrual Health Education in India. *Proc. ACM Hum.-Comput. Interact.* 2, CSCW: 174:1–174:20. <https://doi.org/10.1145/3274443>
86. Anupriya Tuli, Shruti Dalvi, Neha Kumar, and Pushpendra Singh. 2019. “It’s a Girl Thing”: Examining Challenges and Opportunities Around Menstrual Health Education in India. *ACM Trans. Comput.-Hum. Interact.* 26, 5: 29:1–29:24. <https://doi.org/10.1145/3325282>
87. Peter West, Richard Giordano, Max Van Kleek, and Nigel Shadbolt. 2016. The Quantified Patient in the Doctor’s Office: Challenges & Opportunities. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*, 3066–3078. <https://doi.org/10.1145/2858036.2858445>
88. Susan Williams, J. Weinman, and J. Dale. 1998. Doctor–patient communication and patient satisfaction. *Fam Pract* 15, 5: 480–92.
89. Alyson L. Young and Andrew D. Miller. 2019. “This Girl is on Fire”: Sensemaking in an Online Health Community for Vulvodynia. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19)*, 129:1–129:13. <https://doi.org/10.1145/3290605.3300359>
90. Haining Zhu, Joanna Colgan, Madhu Reddy, and Eun Kyoung Choe. 2016. Sharing Patient-Generated Data in Clinical Practices: An Interview Study. *AMIA ... Annual Symposium proceedings. AMIA Symposium 2016*: 1303–1312.
91. 2016. MENSTRUAPPS - How to turn your period into money (for others). *chupadados*. Retrieved July 24, 2019 from <https://chupadados.codingrights.org/en/menstruapps-como-transformar-sua-menstruacao-em-dinheiro-para-os-outros/>
92. WHO | Global prevalence of infertility, infecundity and childlessness. *WHO*. Retrieved May 31, 2020 from <https://www.who.int/reproductivehealth/topics/infertility/burden/en/>
93. WHO | Infertility is a global public health issue. *WHO*. Retrieved June 5, 2017 from <http://www.who.int/reproductivehealth/topics/infertility/perspective/en/>
94. Infertility | Reproductive Health | CDC. Retrieved July 6, 2017 from <https://www.cdc.gov/reproductivehealth/infertility/index.htm>