Opportunities and Risks for Engaging Research Participants with Self-Logged Menstrual Health Data

Samantha Robertson
samantha_robertson@berkeley.edu
University of California, Berkeley
Department of Electrical Engineering and Computer Sciences
Berkeley, California, USA

Kim G. Harley
kharley@berkeley.edu
University of California, Berkeley
Wallace Center for Maternal, Child, and Adolescent Health, School of Public Health
Berkeley, California, USA

Niloufar Salehi
nsalehi@berkeley.edu
University of California, Berkeley
School of Information
Berkeley, California, USA

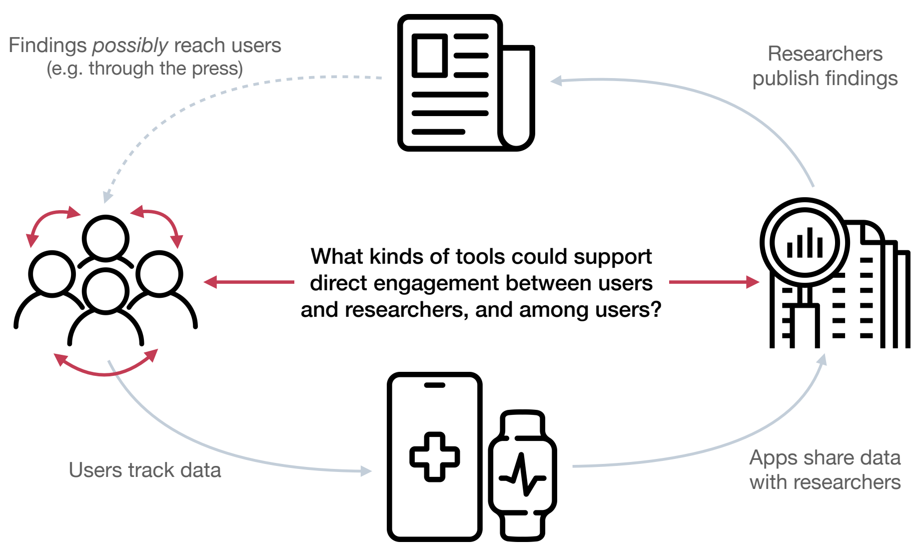

Figure 1: It is increasingly common for researchers to use data from personal health tracking apps in menstrual health research, but this work rarely engages directly with the users who contributed the data. Our work explores how adding research participants into the data analysis loop could help users understand more about their health, and improve the quality of research conducted with this data.

ABSTRACT

Many people use health tracking apps to keep track of their menstrual cycles, often in the hopes of better understanding their own health, and being able to identify when something might be wrong. However, it can be very difficult to interpret this data alone. Meanwhile, it is becoming increasingly common for researchers to use data from these apps to learn more about menstrual health. In this work we ask, how could more participatory approaches to conducting menstrual health research benefit both participants and researchers? We identify key challenges and risks of this kind of engagement, and propose four design guidelines for human-in-the-loop data analysis tools that engage participants with large-scale, quantitative menstrual health research: surface and elicit feedback on the data cleaning and analysis procedure; convey information relative to other users and clinical guidance; structure engagement to ensure valid analyses; and support social engagement and learning. For each of these, we highlight key open research questions relevant to the HILDA and visualization research communities. We plan to for evaluate and iterate on these guidelines through design workshops with users, researchers, and healthcare providers.

KEYWORDS

personal health informatics, data visualization, participatory research

HILDA '22 , June 12, 2022, Philadelphia, PA, USA

ACM ISBN 978-1-4503-9442-0/22/06.
https://doi.org/10.1145/3546930.3547501

ACM Reference Format:
Samantha Robertson, Kim G. Harley, and Niloufar Salehi. 2022. Opportunities and Risks for Engaging Research Participants with Self-Logged Menstrual Health Data. In *Workshop on Human-In-the-Loop Data Analytics (HILDA '22), June 12, 2022, Philadelphia, PA, USA.* ACM, New York, NY, USA, 7 pages. https://doi.org/10.1145/3546930.3547501

1 INTRODUCTION

As more people have started using technology for tracking their health and habits [20, 27], researchers have become interested in using that data for scientific research. For example, with the growing popularity of apps for tracking menstrual cycles [23, 60], this has become a popular approach in menstrual health research [30, 57, 73, 77]. The findings of this research could help users of menstrual tracking apps improve their understanding of their own cycles relative to others', and learn more about menstrual health more broadly [8, 12, 13, 17, 24, 44, 52, 75, 86]. Users could also provide useful insights and feedback on the research, drawing on their lived expertise and deep contextual knowledge of their data [53, 74]. However, most of this research is not currently conducted in a way that fosters bidirectional learning between researchers and participants (Fig 1). Our work seeks to understand whether, and if so what kind of, interactive data tools could foster this kind of engagement in a way that maximizes benefits and minimizes risks to users. In this paper we define and motivate a research agenda to develop more open and collaborative methods for conducting research with personal data.

We focus on menstrual tracking and menstrual health research as a case study. People track their menstrual cycles to build general self-awareness [23, 27], to manage and plan around their periods [23, 51] or symptoms of specific conditions like fibroids, endometriosis, or bleeding disorders [8, 51], to conceive or avoid pregnancy [12, 23, 27, 52], and to learn about menstrual health generally. However, it is difficult for users to derive meaningful and interesting insights from their data with existing tools, especially without clinical guidance [7, 46] or the ability to compare their experiences to others' [13]. Although researchers have developed a wide variety of bespoke visualizations to engage people with self-tracking data [1, 2, 10, 19, 21, 25, 26, 33, 34, 37–42, 47, 50, 64, 69–72], most have focused on individuals engaging with their own data, often in domains like wellness and productivity, where users' goals are more often oriented towards behavior change, and the public has greater general knowledge about the domain [20, 23].

In an ongoing research project, we are using self-logged menstrual cycle data from over 6,000 users of a menstrual tracking app, Clue by BioWink GmbH, to understand how menstrual cycle characteristics in adolescents are associated with factors like stress, and sleep. This research presents an opportunity to actively engage participants in analyzing their own data, and comparing it to the study population. In this paper, we explore the possible benefits of increasing participation in research with menstrual tracking data, as well as potential risks and challenges. We propose four design guidelines for systems that could support this kind of engagement: surface and elicit feedback on the data cleaning and analysis procedure; convey information relative to other users and clinical guidance; structure engagement to ensure valid analyses; and support social engagement and learning. We plan to test and iterate on these guidelines through design workshops with users, researchers, and healthcare providers.

Engaging users who may have limited knowledge of both menstrual health and data analysis in collaborative engagement with researchers around menstrual health data opens up new directions for research into human-in-the-loop data analysis tools. For instance, how can we engage a large group of people in analyzing, sharing, and co-learning with and through their collective data? How can we help people interpret their data in the context of a broader sample in a way that accounts for uncertainty and the wide variability in menstrual cycle characteristics? How can we incorporate expert guidance into the data exploration experience without being overly prescriptive about how users can explore their data? We look forward to feedback from the HILDA community about how we can adapt the tools that have been developed in this field to this new domain of menstrual health.

2 ENGAGING PARTICIPANTS IN RESEARCH WITH PERSONAL DATA: BENEFITS AND CHALLENGES

Across disciplines, researchers have worked to foster collaboration with participants in their studies. For example, the participatory research and citizen science methodologies center participants as key contributors to the work, from formulating research questions, to collecting and interpreting data [18, 36]. In this section we draw on literature from these traditions to motivate our work and anticipate risks and challenges.

2.1 Benefits

Engaging with menstrual health research using tracking data could **help participants learn more about their own health & menstrual health more broadly,** a key goal for many people who track their periods [8, 12, 13, 24, 44, 51, 52, 75, 86]. Both the participatory research and citizen science traditions emphasize the importance of sharing findings with those who contributed to the research, with participants' learning being a key benefit of this practice [3, 4, 29, 76]. Prior work has found that tracking app users are interested in comparing their data to others', and some even share their data online when comparison is not supported by existing tools [13, 82]. Allowing users to explore their own data relative to a research study cohort could support these kinds of comparisons and help users interpret their data. Engaging users in research also offers opportunities for them to **learn about the research process and improve their data literacy** [43, 76].

Participatory research not only offers educational opportunities for participants, but also **enables researchers to draw on participants' lived experiences and contextual expertise**. External context is invaluable to the interpretation of personal data [53, 74]. For example, a participant in Moore et al.'s study of home air quality data associated large spikes in poor air quality with times they had cooked bacon – an insight that researchers working with this data could never have derived alone [53]. People's contextual understanding of their data could improve many stages of the research process, from forming relevant and previously overlooked hypotheses [51], to more accurate data cleaning and aggregation [53]. For example, a major challenge in the context of menstrual tracking data is filtering lapses in app usage. Users may be able to provide much more accurate information about their cycles and app usage than could be inferred from the data alone.

Finally, our work is an opportunity to **increase participant awareness and oversight of large-scale quantitative research.** A 2014 study conducted as part of the Health Data Exploration Project found that people are open to sharing their personal health data with researchers, as long as they know it will not be used for commercial purposes and that the research will have some personal or public benefit [58]. McKillop et al. conducted workshops with women with endometriosis, and also found that they were open to participating in research involving self-logged personal data, especially if the research would help younger people with the condition [51]. Unfortunately, research with large-scale personal data has not always met participants' expectations [32, 66]. This has led to calls for ensuring that data subjects are aware of research conducted with their data, and have some power to shape the kinds of questions asked and how the benefits of the research are distributed [59, 66].

2.2 Risks and Challenges

Achieving these benefits in practice will be challenging, especially at the scale of many quantitative research studies, which can involve thousands, or even millions, of participants distributed around the world [57].

An important challenge will be **preventing misinterpretation, over-diagnosis, and unnecessary concern** for users. One of the major issues with existing personal health technologies is a lack of clinical validation [16, 24, 88]. Period tracking apps have had to withdraw even clinically validated diagnostic screening tools after they raised concern about over-diagnosis and unnecessary stress for users [67]. In the context of fertility tracking, research has found that aggregating data across users can help individuals better interpret their own data, but it can also enforce norms and generate stress and anxiety, especially when it is unclear how clincially valid the aggregate analyses are [13]. This presents a difficult trade-off between empowering people to better understand their health, and exercising caution to avoid misinformation and unnecessary stress. Researchers across the health sciences have grappled with this challenge and put forth best practices, such as providing personalized support and clinical guidelines to help people interpret study results [6, 54], but these practices remain contested [54]. One goal of this work is to better understand these risks and develop mitigation strategies in the context of participant engagement with menstrual health research with tracking-data.

Another critical challenge will be **protecting participants' privacy**. Menstrual cycles and other personal health data are extremely personal and intimate data sources, and users' privacy must be a top priority. Tools for engaging with research data must be carefully designed to protect individuals' and vulnerable subpopulations' information. Unfortunately, many period tracking apps have violated users' trust by selling their data to third parties [31]. Although research suggests that many people are open to sharing data with researchers, it is not clear how many users know how their data is used, and by whom, nor do we have a clear understanding of tracking app users' contextual expectations of privacy [58]. A first step towards this understanding is ensuring that participants are aware of how their data is being used, and give them more opportunities to opt out of participating. Engaging users with this kind of research more actively could be a useful way to begin developing norms and expectations around privacy, and empower users to advocate for their privacy and make informed decisions about technology use. While the remainder of this paper focuses on ways to engage users with research in a way that maximizes benefits and mitigates risk, we recognize that we may find in the course of developing this work that the risks of such engagement may outweigh the benefits.

3 DESIGN GUIDELINES

Engaging users and researchers with personal health data in a mutually beneficial way will require interactive systems that allow users to explore their data with neither technical nor domain expertise. Research in the human-in-the-loop data analytics (HILDA) and broader data visualization community has explored ways of making it easier for a range of audiences to engage with large-scale quantitative data. For example, interfaces that allow users to build visualizations using natural language [28, 63, 65], or demonstrations (e.g. other visualizations, sketches, or constraints) [61, 62, 68, 80, 81, 84, 85], or that recommend relevant visualizations based on partial specifications [49, 55, 83] or interesting patterns in a dataset [37, 38, 45] all have great potential for allowing end-users of self-tracking apps to freely explore and visualize their data without needing to code.

However, many existing tools for analyzing and visualizing data without needing to write code have been designed for domain experts. People who use tracking apps may have deep expertise on their own experiences, but many will have limited menstrual health literacy and data literacy. In this section, we discuss four design guidelines for systems to engage these people with research data, informed by prior work on data visualization for personal health data and participatory research. We highlight open research questions relevant to the HILDA community that each of these guidelines raise. Figure 2 envisions how these guidelines might be applied to visualization tools, using menstrual cycle length and regularity as an example. These guidelines are hypotheses about how we might be able to support engagement, maximizing the benefits and mitigating the risks outlined in the previous section, and we plan to test and refine these guidelines in the context of an ongoing menstrual health research project.

(DG1) Surface and elicit feedback on the data cleaning and analysis procedure. How data has been collected, cleaned, and aggregated is often abstracted away in data visualization systems, but it is also an extremely consequential process involving many value-laden decisions [5, 11]. Surfacing this process is key to giving users meaningful oversight of the research, as well as leveraging their expertise to improve the effectiveness of data cleaning. For instance, as mentioned above, a particularly important case for period tracking data is removing cycles where a user stopped using or forgot to use the app. However, it is difficult to communicate complex analysis methods in a way that is digestible and understandable to a broad audience [5, 11]. Providing editing tools for users to annotate these cycles not only gives researchers the opportunity to improve their data cleaning, but also to learn more

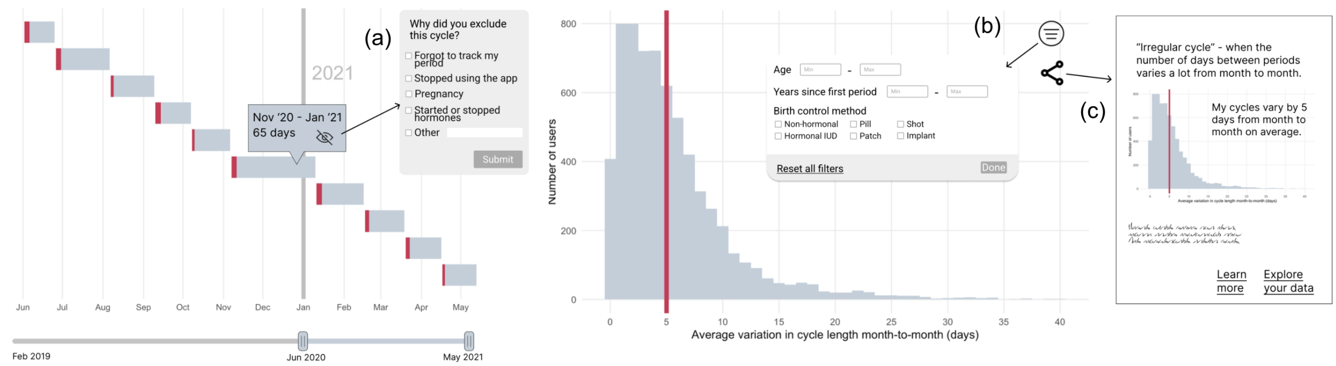

Figure 2: Explorations of how data visualization tools could engage participants with menstrual health research in line with the four guidelines. (a) Users could contribute to data cleaning and provide further insight into their data in the process through short, focused follow-up surveys (DG1). (b) Visualizations should support appropriate comparisons and baselines (DG2). (c) Users should have ways to share what they learn and collaboratively make sense of the data (DG4).

about the data and the participants. For example, users could be asked follow-up survey questions about why they are editing their data (Fig. 2(a)). **Open questions:** How can tools surface the data cleaning and analysis methods in a way that is understandable and useful to participants? How can we elicit feedback from users in a way that can be integrated back into the analysis procedure? How can we ensure that users understand how their feedback has been accounted for?

(DG2) Convey uncertainty and variability when making comparisons. Comparison against baselines and peers is important for users to be able to contextualize and interpret their data [6, 13, 35, 37] (Fig. 2(b)). However, comparison can also promote strict norms and create stress for those who appear to fall outside of them [13]. Tools should provide information to help people interpret these comparisons, mitigate unnecessary stress, and connect users to healthcare providers or other sources of support [6, 54]. It is an open question how visualizations can or should convey bad news and have an appropriate impact on an audience [6, 11], and this is likely to be even more challenging when a visualization is conveying information about the viewer's own health, since people engage most with visualizations that they can directly relate to [56]. This issue is complicated by the fact that menstrual cycles are extremely variable and individual, so comparative visualizations may often look concerning to a user when they have nothing to worry about. On the other hand, many people who do have health conditions related to their menstrual cycles, e.g. endometriosis, struggle for years to get a diagnosis [13]. There is a balance to strike between avoiding unnecessary concern and over-diagnosis, while also not dismissing people's valid health concerns [8]. **Open questions:** How should we visualize uncertainty in the context of highly variable and individualized distributions? Can uncertainty visualization mitigate unncessary stress and over-diagnosis? What are the implications of allowing comparative analyses for individual and sub-group privacy? Could we automatically detect when someone views a visualization that might be worrisome and offer relevant resources?

(DG3) Structure engagement to ensure valid analyses. Ideally, participants should be able to explore the data flexibly and answer questions that are most personally relevant to them. Tools that allow users to create visualizations using direct manipulation and/or natural language [28, 61–63, 65, 68, 80, 81, 84, 85], or even visualization recommendation systems [37, 38, 45, 49, 55, 83], are likely to be important to support creative and open-ended engagement. A challenge with supporting open-ended exploration, however, will be ensuring that users do not conduct meaningless or misleading analyses [11, 87]. Identifying questions that can be answered with a given dataset is challenging even for experienced analysts [14]. Engagement should therefore allow open-ended engagement as much as possible while remaining structured enough to guide users to valid analyses and interpretations. For example, users should be guided towards reasonable comparisons and baselines, and away from trying to make causal inferences from observational data. **Open questions:** Can we automatically detect when a user tries to conduct an analysis that is not well supported by the data? How can we interactively teach users how to ask valid questions and interpret their results?

(DG4) Support social engagement and learning. Research on personal health informatics is increasingly acknowledging the social dimensions of health tracking [9, 22, 48, 78]. Social engagement, even if passive, is important for learning [15, 75, 79] and can be a source of support, particularly for people with chronic health conditions [8, 44]. Much of this kind of support and collective sensemaking defies quantification and analysis in the way that would be supported by engaging people on an isolated, individual basis with quantitative menstrual health research. **Open questions:** How can we support asynchronous and (possibly) anonymous collaboration in understanding and contributing to quantitative health research? How does social engagement mitigate or worsen the risks of misinformation and over-diagnosis?

4 FUTURE WORK

The guidelines we have proposed are hypotheses informed by prior literature, and will need to be tested and validated before being more widely used in the field. The first two authors are currently using data from Clue by BioWink GmbH, a popular period tracking app, to characterize menstrual cycles in adolescents, and investigate how cycle characteristics are associated with behavioral factors like sleep and stress. Our future work will involve engaging participants with this research more deeply, evaluating and adapting these guidelines in the process.

In the longer term, we hope to see research conducted in collaboration with participants from generating research questions and hypotheses, through to dissemination. We believe the HILDA community can play a critical role in building tools to support this vision.

5 CONCLUSION

In this paper we argued that engaging participants directly in research with large-scale data from menstrual cycle tracking apps has great potential to benefit participants and improve research. However, this engagement will not be without risk, especially around misinterpretation and over-diagnosis, and privacy. We presented early design guidelines for systems that could support this engagement, and described our plans to evaluate and iterate on them through design workshops. We look forward to feedback from the HILDA community about how we can extend tools for exploring and visualizing data without code, as well as how to visualize individuals' data in the context of an uncertain and highly variable distribution.

ACKNOWLEDGMENTS

We are deeply grateful to the Clue users who have participated in our research and inspired this work. We would also like to thank Amanda Shea and Charlie Upton from Clue by BioWink GmbH for their ongoing support. We are grateful to Leilani Battle and the members of the EPIC lab at U.C. Berkeley for their helpful feedback on this work.

REFERENCES

[1] Bon Adriel Aseniero, Charles Perin, Wesley Willett, Anthony Tang, and Sheelagh Carpendale. 2020. Activity River: Visualizing Planned and Logged Personal Activities for Reflection. In *Proceedings of the International Conference on Advanced Visual Interfaces*. ACM, Salerno Italy, 1–9. https://doi.org/10.1145/3399715.3399921

[2] Frank Bentley, Konrad Tollmar, Peter Stephenson, Laura Levy, Brian Jones, Scott Robertson, Ed Price, Richard Catrambone, and Jeff Wilson. 2013. Health Mashups: Presenting Statistical Patterns between Wellbeing Data and Context in Natural Language to Promote Behavior Change. *ACM Transactions on Computer-Human Interaction* 20, 5 (Nov. 2013), 1–27. https://doi.org/10.1145/2503823

[3] Rick Bonney, Caren B. Cooper, Janis Dickinson, Steve Kelling, Tina Phillips, Kenneth V. Rosenberg, and Jennifer Shirk. 2009. Citizen Science: A Developing Tool for Expanding Science Knowledge and Scientific Literacy. *BioScience* 59, 11 (Dec. 2009), 977–984. https://doi.org/10.1525/bio.2009.59.11.9

[4] Rick Bonney, Tina B. Phillips, Heidi L. Ballard, and Jody W. Enck. 2016. Can citizen science enhance public understanding of science? *Public Understanding of Science* 25, 1 (Jan. 2016), 2–16. https://doi.org/10.1177/0963662515607406 Publisher: SAGE Publications Ltd.

[5] Alyxander Burns, Thai On, Christiana Lee, Rachel Shapiro, Cindy Xiong, and Narges Mahyar. 2021. Making the Invisible Visible: Risks and Benefits of Disclosing Metadata in Visualization. In *Workshop on Visualization for Social Good Workshop at IEEE VIS 2021*.

[6] Eun Kyoung Choe, Marisa E Duarte, Hyewon Suh, Wanda Pratt, and Julie A Kientz. 2019. Communicating Bad News: Insights for the Design of Consumer Health Technologies. *JMIR Human Factors* 6, 2 (May 2019), e8885. https://doi.org/10.2196/humanfactors.8885

[7] 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)*. Association for Computing Machinery, New York, NY, USA, 1143–1152. https://doi.org/10.1145/2556288.2557372

[8] Shaan Chopra, Rachael Zehrung, Tamil Arasu Shanmugam, and Eun Kyoung Choe. 2021. Living with Uncertainty and Stigma: Self-Experimentation and Support-Seeking around Polycystic Ovary Syndrome. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems* (Yokohama, Japan) *(CHI '21)*. Association for Computing Machinery, New York, NY, USA, Article 202, 18 pages. https://doi.org/10.1145/3411764.3445706

[9] Chia-Fang Chung, Elena Agapie, Jessica Schroeder, Sonali Mishra, James Fogarty, and Sean A. Munson. 2017. When Personal Tracking Becomes Social: Examining the Use of Instagram for Healthy Eating. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, Denver Colorado USA, 1674–1687. https://doi.org/10.1145/3025453.3025747

[10] Sunny Consolvo, Predrag Klasnja, David W. McDonald, Daniel Avrahami, Jon Froehlich, Louis LeGrand, Ryan Libby, Keith Mosher, and James A. Landay. 2008. Flowers or a robot army? encouraging awareness & activity with personal, mobile displays. In *Proceedings of the 10th international conference on Ubiquitous computing (UbiComp '08)*. Association for Computing Machinery, New York, NY, USA, 54–63. https://doi.org/10.1145/1409635.1409644

[11] Michael Correll. 2019. Ethical Dimensions of Visualization Research. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) *(CHI '19)*. Association for Computing Machinery, New York, NY, USA, 1–13. https://doi.org/10.1145/3290605.3300418

[12] 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. *Proceedings of the ACM on Human-Computer Interaction* 1, CSCW (Dec. 2017), 36:1–36:21. https://doi.org/10.1145/3134671

[13] Mayara Costa Figueiredo and Yunan Chen. 2021. Health Data in Fertility Care: An Ecological Perspective. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. Number 204. Association for Computing Machinery, New York, NY, USA, 1–17. https://doi.org/10.1145/3411764.3445189

[14] Anamaria Crisan, Brittany Fiore-Gartland, and Melanie Tory. 2021. Passing the Data Baton : A Retrospective Analysis on Data Science Work and Workers. *IEEE Transactions on Visualization and Computer Graphics* 27, 2 (2021), 1860–1870. https://doi.org/10.1109/TVCG.2020.3030340

[15] Catalina M. Danis, Fernanda B. Viegas, Martin Wattenberg, and Jesse Kriss. 2008. Your place or mine?: visualization as a community component. In *Proceeding of the twenty-sixth annual CHI conference on Human factors in computing systems - CHI '08*. ACM Press, Florence, Italy, 275. https://doi.org/10.1145/1357054.1357102

[16] Anjali Devakumar, Jay Modh, Bahador Saket, Eric P. S. Baumer, and Munmun De Choudhury. 2021. A Review on Strategies for Data Collection, Reflection, and Communication in Eating Disorder Apps. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems*. ACM, Yokohama Japan, 1–19. https://doi.org/10.1145/3411764.3445670

[17] Anna Druet. 2018. Scientific research at Clue: How tracking your cycle advances female health. *Clue* (March 2018). https://helloclue.com/articles/about-clue/scientific-research-at-clue

[18] P.B. English, M.J. Richardson, and C. Garzón-Galvis. 2018. From Crowdsourcing to Extreme Citizen Science: Participatory Research for Environmental Health. *Annual Review of Public Health* 39, 1 (2018), 335–350. https://doi.org/10.1146/annurev-publhealth-040617-013702 _eprint: https://doi.org/10.1146/annurev-publhealth-040617-013702.

[19] Daniel Epstein, Felicia Cordeiro, Elizabeth Bales, James Fogarty, and Sean Munson. 2014. Taming data complexity in lifelogs: exploring visual cuts of personal informatics data. In *Proceedings of the 2014 conference on Designing interactive systems (DIS '14)*. Association for Computing Machinery, New York, NY, USA, 667–676. https://doi.org/10.1145/2598510.2598558

[20] Daniel A. Epstein, Clara Caldeira, Mayara Costa Figueiredo, Xi Lu, Lucas M. Silva, Lucretia Williams, Jong Ho Lee, Qingyang Li, Simran Ahuja, Qiuer Chen, Payam Dowlatyari, Craig Hilby, Sazeda Sultana, Elizabeth V. Eikey, and Yunan Chen. 2020. Mapping and Taking Stock of the Personal Informatics Literature. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies* 4, 4 (Dec. 2020), 1–38. https://doi.org/10.1145/3432231

[21] Daniel A. Epstein, Mira Dontcheva, James Fogarty, and Sean A. Munson. 2020. Yarn: Adding Meaning to Shared Personal Data through Structured Storytelling. In *Proceedings of Graphics Interface 2020* (University of Toronto) *(GI 2020)*. Canadian Human-Computer Communications Society, 168 – 182. https://doi.org/10.20380/GI2020.18

[22] Daniel A. Epstein, Bradley H. Jacobson, Elizabeth Bales, David W. McDonald, and Sean A. Munson. 2015. From "nobody cares" to "way to go!": A Design Framework for Social Sharing in Personal Informatics. In *Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing*. ACM, Vancouver BC Canada, 1622–1636. https://doi.org/10.1145/2675133.2675135

[23] 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). Association for Computing Machinery, New York, NY, USA, 6876–6888. https://doi.org/10.1145/3025453.3025635

[24] Jordan Eschler, Amanda Menking, Sarah Fox, and Uba Backonja. 2019. Defining Menstrual Literacy With the Aim of Evaluating Mobile Menstrual Tracking Applications. *Computers, informatics, nursing: CIN* 37, 12 (Dec. 2019), 638–646. https://doi.org/10.1097/CIN.0000000000000559

[25] Chloe Fan, Jodi Forlizzi, and Anind K. Dey. 2012. A spark of activity: exploring informative art as visualization for physical activity. In *Proceedings of the 2012 ACM Conference on Ubiquitous Computing (UbiComp '12)*. Association for Computing Machinery, New York, NY, USA, 81–84. https://doi.org/10.1145/2370216.2370229

[26] Jon Froehlich, Leah Findlater, Marilyn Ostergren, Solai Ramanathan, Josh Peterson, Inness Wragg, Eric Larson, Fabia Fu, Mazhengmin Bai, Shwetak Patel, and James A. Landay. 2012. The design and evaluation of prototype eco-feedback displays for fixture-level water usage data. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*. Association for Computing Machinery, New York, NY, USA, 2367–2376. https://doi.org/10.1145/2207676.2208397

[27] Katie Gambier-Ross, David J McLernon, and Heather M Morgan. 2018. A mixed methods exploratory study of women's relationships with and uses of fertility tracking apps. *Digital Health* 4 (July 2018), 2055207618785077. https://doi.org/10.1177/2055207618785077

[28] Tong Gao, Mira Dontcheva, Eytan Adar, Zhicheng Liu, and Karrie G. Karahalios. 2015. DataTone: Managing Ambiguity in Natural Language Interfaces for Data Visualization. In *Proceedings of the 28th Annual ACM Symposium on User Interface Software & Technology* (Charlotte, NC, USA) *(UIST '15)*. Association for Computing Machinery, New York, NY, USA, 489–500. https://doi.org/10.1145/2807442.2807478

[29] Margaret Gold. 2019. ECSA 10 Principles of Citizen Science. (Jan. 2019). https://doi.org/10.17605/OSF.IO/XPR2N Publisher: OSF.

[30] Jessica Grose. 2021. Why Is Perimenopause Still Such a Mystery? *New York Times* (April 2021). https://www.nytimes.com/2021/04/29/well/perimenopause-women.html?smid=tw-share

[31] Alisha Haridasani Gupta and Natasha Singer. 2021. Your App Knows You Got Your Period. Guess Who It Told? *New York Times* (Jan 2021). https://www.nytimes.com/2021/01/28/us/period-apps-health-technology-women-privacy.html

[32] Blake Hallinan, Jed R Brubaker, and Casey Fiesler. 2020. Unexpected expectations: Public reaction to the Facebook emotional contagion study. *New Media & Society* 22, 6 (2020), 1076–1094. https://doi.org/10.1177/1461444819876944 arXiv:https://doi.org/10.1177/1461444819876944

[33] Steven Houben, Connie Golsteijn, Sarah Gallacher, Rose Johnson, Saskia Bakker, Nicolai Marquardt, Licia Capra, and Yvonne Rogers. 2016. Physikit: Data Engagement Through Physical Ambient Visualizations in the Home. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, San Jose California USA, 1608–1619. https://doi.org/10.1145/2858036.2858059

[34] Cheng-Kang Hsieh, Hongsuda Tangmunarunkit, Faisal Alquaddoomi, John Jenkins, Jinha Kang, Cameron Ketcham, Brent Longstaff, Joshua Selsky, Betta Dawson, Dallas Swendeman, Deborah Estrin, and Nithya Ramanathan. 2013. Lifestreams: a modular sense-making toolset for identifying important patterns from everyday life. In *Proceedings of the 11th ACM Conference on Embedded Networked Sensor Systems (SenSys '13)*. Association for Computing Machinery, New York, NY, USA, 1–13. https://doi.org/10.1145/2517351.2517368

[35] Dandan Huang, Melanie Tory, Bon Adriel Aseniero, Lyn Bartram, Scott Bateman, Sheelagh Carpendale, Anthony Tang, and Robert Woodbury. 2015. Personal Visualization and Personal Visual Analytics. *IEEE Transactions on Visualization and Computer Graphics* 21, 3 (2015), 420–433. https://doi.org/10.1109/TVCG.2014.2359887

[36] Barbara A. Israel, Amy J. Schulz, Edith A. Parker, and Adam B. Becker. 1998. REVIEW OF COMMUNITY-BASED RESEARCH: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health* 19, 1 (1998), 173–202. https://doi.org/10.1146/annurev.publhealth.19.1.173 _eprint: https://doi.org/10.1146/annurev.publhealth.19.1.173.

[37] Simon L. Jones. 2015. Exploring correlational information in aggregated quantified self data dashboards. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing and Proceedings of the 2015 ACM International Symposium on Wearable Computers - UbiComp '15*. ACM Press, Osaka, Japan, 1075–1080. https://doi.org/10.1145/2800835.2800963

[38] Simon L. Jones and Ryan Kelly. 2018. Dealing With Information Overload in Multifaceted Personal Informatics Systems. *Human–Computer Interaction* 33, 1 (Jan. 2018), 1–48. https://doi.org/10.1080/07370024.2017.1302334

[39] Rohit Ashok Khot, Jeewon Lee, Deepti Aggarwal, Larissa Hjorth, and Florian 'Floyd' Mueller. 2015. TastyBeats: Designing Palatable Representations of Physical Activity. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, Seoul Republic of Korea, 2933–2942. https://doi.org/10.1145/2702123.2702197

[40] Rohit Ashok Khot, Florian 'Floyd' Mueller, and Larissa Hjorth. 2013. SweatAtoms: materializing physical activity. In *Proceedings of The 9th Australasian Conference on Interactive Entertainment Matters of Life and Death - IE '13*. ACM Press, Melbourne, Australia, 1–7. https://doi.org/10.1145/2513002.2513012

[41] Young-Ho Kim, Bongshin Lee, Arjun Srinivasan, and Eun Kyoung Choe. 2021. Data@Hand: Fostering Visual Exploration of Personal Data on Smartphones Leveraging Speech and Touch Interaction. *arXiv:2101.06283 [cs]* (Jan. 2021). https://doi.org/10.1145/3411764.3445421 arXiv: 2101.06283.

[42] Yea-Seul Kim, Katharina Reinecke, and Jessica Hullman. 2017. Explaining the Gap: Visualizing One's Predictions Improves Recall and Comprehension of Data. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, Denver Colorado USA, 1375–1386. https://doi.org/10.1145/3025453.3025592

[43] Anne M. Land-Zandstra, Jeroen L. A. Devilee, Frans Snik, Franka Buurmeijer, and Jos M. van den Broek. 2016. Citizen science on a smartphone: Participants' motivations and learning. *Public Understanding of Science* 25, 1 (Jan. 2016), 45–60. https://doi.org/10.1177/0963662515602406 Publisher: SAGE Publications Ltd.

[44] 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*. Association for Computing Machinery, New York, NY, USA, 1–16. https://doi.org/10.1145/3290605.3300710

[45] Doris Jung-Lin Lee, Dixin Tang, Kunal Agarwal, Thyne Boonmark, Caitlyn Chen, Jake Kang, Ujjaini Mukhopadhyay, Jerry Song, Micah Yong, Marti A. Hearst, and Aditya G. Parameswaran. 2021. Lux: Always-on Visualization Recommendations for Exploratory Dataframe Workflows. *Proc. VLDB Endow.* 15, 3 (nov 2021), 727–738. https://doi.org/10.14778/3494124.3494151

[46] 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)*. Association for Computing Machinery, New York, NY, USA, 557–566. https://doi.org/10.1145/1753326.1753409

[47] James J. Lin, Lena Mamykina, Silvia Lindtner, Gregory Delajoux, and Henry B. Strub. 2006. Fish'n'Steps: encouraging physical activity with an interactive computer game. In *Proceedings of the 8th international conference on Ubiquitous Computing (UbiComp'06)*. Springer-Verlag, Berlin, Heidelberg, 261–278. https://doi.org/10.1007/11853565_16

[48] Xi Lu, Yunan Chen, and Daniel A. Epstein. 2021. A Model of Socially Sustained Self-Tracking for Food and Diet. *Proceedings of the ACM on Human-Computer Interaction* 5, CSCW2 (Oct. 2021), 1–32. https://doi.org/10.1145/3479595

[49] Jock Mackinlay, Pat Hanrahan, and Chris Stolte. 2007. Show Me: Automatic Presentation for Visual Analysis. *IEEE Transactions on Visualization and Computer Graphics* 13, 6 (2007), 1137–1144. https://doi.org/10.1109/TVCG.2007.70594

[50] 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)*. Association for Computing Machinery, New York, NY, USA, 477–486. https://doi.org/10.1145/1357054.1357131

[51] 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*. ACM, Montreal QC Canada, 1–15. https://doi.org/10.1145/3173574.3174139

[52] Maryam Mehrnezhad and Teresa Almeida. 2021. Caring for Intimate Data in Fertility Technologies. In *Proceedings of the 2021 CHI Conference on Human Factors in Computing Systems (CHI '21)*. Association for Computing Machinery, New York, NY, USA, 1–11. https://doi.org/10.1145/3411764.3445132

[53] Jimmy Moore, Pascal Goffin, Jason Wiese, and Miriah Meyer. 2021. Exploring the Personal Informatics Analysis Gap: "There's a Lot of Bacon". *IEEE Transactions on Visualization and Computer Graphics* (2021), 1–1. https://doi.org/10.1109/TVCG.2021.3114798 arXiv: 2108.03761.

[54] Rachel Morello-Frosch, Julia Green Brody, Phil Brown, Rebecca Gasior Altman, Ruthann A. Rudel, Carla Pérez, and Alison Cohen. 2011. *Contested Illnesses : Citizens, Science, and Health Social Movements*. University of California Press, Chapter Toxic Ignorance and the Right to Know Biomonitoring Results Communication: A Survey of Scientists and Study Participants.

[55] Dominik Moritz, Chenglong Wang, Greg L. Nelson, Halden Lin, Adam M. Smith, Bill Howe, and Jeffrey Heer. 2019. Formalizing Visualization Design Knowledge as Constraints: Actionable and Extensible Models in Draco. *IEEE Transactions on Visualization and Computer Graphics* 25, 1 (2019), 438–448. https://doi.org/10.1109/TVCG.2018.2865240

[56] Evan M. Peck, Sofia E. Ayuso, and Omar El-Etr. 2019. Data is Personal: Attitudes and Perceptions of Data Visualization in Rural Pennsylvania. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems* (Glasgow, Scotland Uk) *(CHI '19)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3290605.3300474

[57] Emma Pierson, Tim Althoff, Daniel Thomas, Paula Hillard, and Jure Leskovec. 2021. Daily, weekly, seasonal and menstrual cycles in women's mood, behaviour and vital signs. *Nature Human Behavior* 5 (2021), 716–725. https://doi.org/10.1038/s41562-020-01046-9

[58] Health Data Exploration Project. 2014. Personal Data for the Public Good: New Opportunities to Enrich Understanding of Individual and Population Health.

[59] Danial Qaurooni, Ali Ghazinejad, Inna Kouper, and Hamid Ekbia. 2016. Citizens for Science and Science for Citizens: The View from Participatory Design. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*

(CHI '16). Association for Computing Machinery, New York, NY, USA, 1822–1826. https://doi.org/10.1145/2858036.2858575

[60] Grand View Research. 2021. Women's Health App Market Size, Share & Trends Analysis Report By Type (Fitness & Nutrition, Pregnancy Tracking & Postpartum Care, Menopause), By Region (North America, Europe, APAC, Latin America, MEA), And Segment Forecasts, 2021 - 2028. https://www.grandviewresearch.com/industry-analysis/womens-health-app-market

[61] Bahador Saket, Hannah Kim, Eli T. Brown, and Alex Endert. 2017. Visualization by Demonstration: An Interaction Paradigm for Visual Data Exploration. *IEEE Transactions on Visualization and Computer Graphics* 23, 1 (2017), 331–340. https://doi.org/10.1109/TVCG.2016.2598839

[62] David Schroeder and Daniel F. Keefe. 2016. Visualization-by-Sketching: An Artist's Interface for Creating Multivariate Time-Varying Data Visualizations. *IEEE Transactions on Visualization and Computer Graphics* 22, 1 (2016), 877–885. https://doi.org/10.1109/TVCG.2015.2467153

[63] Vidya Setlur, Sarah E. Battersby, Melanie Tory, Rich Gossweiler, and Angel X. Chang. 2016. Eviza: A Natural Language Interface for Visual Analysis. In *Proceedings of the 29th Annual Symposium on User Interface Software and Technology*. ACM, Tokyo Japan, 365–377. https://doi.org/10.1145/2984511.2984588

[64] Moushumi Sharmin, Andrew Raij, David Epstien, Inbal Nahum-Shani, J. Gayle Beck, Sudip Vhaduri, Kenzie Preston, and Santosh Kumar. 2015. Visualization of Time-Series Sensor Data to Inform the Design of Just-In-Time Adaptive Stress Interventions. *Proceedings of the ... ACM International Conference on Ubiquitous Computing . UbiComp (Conference)* 2015 (Sept. 2015), 505–516. https://doi.org/10.1145/2750858.2807537

[65] Leixian Shen, Enya Shen, Yuyu Luo, Xiaocong Yang, Xuming Hu, Xiongshuai Zhang, Zhiwei Tai, and Jianmin Wang. 2021. Towards Natural Language Interfaces for Data Visualization: A Survey. *arXiv:2109.03506 [cs]* (Sept. 2021). http://arxiv.org/abs/2109.03506 arXiv: 2109.03506.

[66] Katie Shilton, Emanuel Moss, Sarah A. Gilbert, Matthew J. Bietz, Casey Fiesler, Jacob Metcalf, Jessica Vitak, and Michael Zimmer. 2021. Excavating awareness and power in data science: A manifesto for trustworthy pervasive data research. *Big Data & Society* 8, 2 (July 2021), 20539517211040759. https://doi.org/10.1177/20539517211040759 Publisher: SAGE Publications Ltd.

[67] Natasha Singer. 2019. Period-Tracking Apps Say You May Have a Disorder. What if They're Wrong? *New York Times* (Oct 2019). nytimes.com/2019/10/27/technology/personaltech/health-apps-hormonal-disorder-pcos.html

[68] Chris Stolte, Diane Tang, and Pat Hanrahan. 2008. Polaris: A System for Query, Analysis, and Visualization of Multidimensional Databases. *Commun. ACM* 51, 11 (nov 2008), 75–84. https://doi.org/10.1145/1400214.1400234

[69] Simon Stusak, Aurélien Tabard, Franziska Sauka, Rohit Ashok Khot, and Andreas Butz. 2014. Activity Sculptures: Exploring the Impact of Physical Visualizations on Running Activity. *IEEE Transactions on Visualization and Computer Graphics* 20, 12 (Dec. 2014), 2201–2210. https://doi.org/10.1109/TVCG.2014.2352953 Conference Name: IEEE Transactions on Visualization and Computer Graphics.

[70] Anja Thieme, Rob Comber, Julia Miebach, Jack Weeden, Nicole Kraemer, Shaun Lawson, and Patrick Olivier. 2012. "We've bin watching you": designing for reflection and social persuasion to promote sustainable lifestyles. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*. Association for Computing Machinery, New York, NY, USA, 2337–2346. https://doi.org/10.1145/2207676.2208394

[71] Alice Thudt, Dominikus Baur, Samuel Huron, and Sheelagh Carpendale. 2016. Visual Mementos: Reflecting Memories with Personal Data. *IEEE Transactions on Visualization and Computer Graphics* 22, 1 (Jan. 2016), 369–378. https://doi.org/10.1109/TVCG.2015.2467831 Conference Name: IEEE Transactions on Visualization and Computer Graphics.

[72] Alice Thudt, Uta Hinrichs, Samuel Huron, and Sheelagh Carpendale. 2018. Self-Reflection and Personal Physicalization Construction. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, Montreal QC Canada, 1–13. https://doi.org/10.1145/3173574.3173728

[73] Ida Tin. 2017. What promise do data and Femtech hold for female health? *Clue* (nov 2017). https://helloclue.com/articles/culture/what-promise-do-data-femtech-hold-for-female-health

[74] Peter Tolmie, Andy Crabtree, Tom Rodden, James Colley, and Ewa Luger. 2016. "This has to be the cats": Personal Data Legibility in Networked Sensing Systems. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, San Francisco California USA, 491–502. https://doi.org/10.1145/2818048.2819992

[75] Anupriya Tuli, Shaan Chopra, Neha Kumar, and Pushpendra Singh. 2018. Learning *from* and *with* Menstrupedia: Towards Menstrual Health Education in India. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (Nov. 2018), 174:1–174:20. https://doi.org/10.1145/3274443

[76] Tabea Turrini, Daniel Dörler, Anett Richter, Florian Heigl, and Aletta Bonn. 2018. The threefold potential of environmental citizen science - Generating knowledge, creating learning opportunities and enabling civic participation. *Biological Conservation* 225 (Sept. 2018), 176–186. https://doi.org/10.1016/j.biocon.2018.03.024

[77] Ijeoma Unachukwu. 2021. Why are women and people with cycles underrepresented in health research? *Clue* (jan 2021). https://helloclue.com/articles/culture/why-are-women-and-people-with-cycles-underrepresented-in-health-research

[78] Lisa M. Vizer, Jordan Eschler, Bon Mi Koo, James Ralston, Wanda Pratt, and Sean Munson. 2019. "It's Not Just Technology, It's People": Constructing a Conceptual Model of Shared Health Informatics for Tracking in Chronic Illness Management. *Journal of Medical Internet Research* 21, 4 (April 2019), e10830. https://doi.org/10.2196/10830 Company: Journal of Medical Internet Research Distributor: Journal of Medical Internet Research Institution: Journal of Medical Internet Research Label: Journal of Medical Internet Research Publisher: JMIR Publications Inc., Toronto, Canada.

[79] Jagoda Walny, Sarah Storteboom, Richard Pusch, Steven Munsu Hwang, Søren Knudsen, Sheelagh Carpendale, and Wesley Willett. 2020. PixelClipper: Supporting Public Engagement and Conversation About Visualizations. *IEEE Computer Graphics and Applications* 40, 2 (March 2020), 57–70. https://doi.org/10.1109/MCG.2020.2968906 Conference Name: IEEE Computer Graphics and Applications.

[80] Chenglong Wang, Yu Feng, Rastislav Bodik, Alvin Cheung, and Isil Dillig. 2019. Visualization by Example. *Proc. ACM Program. Lang.* 4, POPL, Article 49 (dec 2019), 28 pages. https://doi.org/10.1145/3371117

[81] Chenglong Wang, Yu Feng, Rastislav Bodik, Isil Dillig, Alvin Cheung, and Amy J Ko. 2021. Falx: Synthesis-Powered Visualization Authoring. (2021), 15.

[82] Paul Wicks, Dorothy L. Keininger, Michael P. Massagli, Christine de la Loge, Catherine Brownstein, Jouko Isojärvi, and James Heywood. 2012. Perceived benefits of sharing health data between people with epilepsy on an online platform. *Epilepsy & Behavior* 23, 1 (2012), 16–23. https://doi.org/10.1016/j.yebeh.2011.09.026

[83] Kanit Wongsuphasawat, Dominik Moritz, Anushka Anand, Jock Mackinlay, Bill Howe, and Jeffrey Heer. 2016. Towards a general-purpose query language for visualization recommendation. In *Proceedings of the Workshop on Human-In-the-Loop Data Analytics - HILDA '16*. ACM Press, San Francisco, California, 1–6. https://doi.org/10.1145/2939502.2939506

[84] Kanit Wongsuphasawat, Dominik Moritz, Anushka Anand, Jock Mackinlay, Bill Howe, and Jeffrey Heer. 2016. Voyager: Exploratory Analysis via Faceted Browsing of Visualization Recommendations. *IEEE Transactions on Visualization and Computer Graphics* 22, 1 (Jan. 2016), 649–658. https://doi.org/10.1109/TVCG.2015.2467191 Conference Name: IEEE Transactions on Visualization and Computer Graphics.

[85] Kanit Wongsuphasawat, Zening Qu, Dominik Moritz, Riley Chang, Felix Ouk, Anushka Anand, Jock Mackinlay, Bill Howe, and Jeffrey Heer. 2017. Voyager 2: Augmenting Visual Analysis with Partial View Specifications. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (Denver, Colorado, USA) *(CHI '17)*. Association for Computing Machinery, New York, NY, USA, 2648–2659. https://doi.org/10.1145/3025453.3025768

[86] 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*. Association for Computing Machinery, New York, NY, USA, 1–13. https://doi.org/10.1145/3290605.3300359

[87] Emanuel Zgraggen, Zheguang Zhao, Robert Zeleznik, and Tim Kraska. 2018. Investigating the Effect of the Multiple Comparisons Problem in Visual Analysis. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (Montreal QC, Canada) *(CHI '18)*. Association for Computing Machinery, New York, NY, USA, 1–12. https://doi.org/10.1145/3173574.3174053

[88] Rhonda Zwingerman, Michael Chaikof, and Claire Jones. 2020. A Critical Appraisal of Fertility and Menstrual Tracking Apps for the iPhone. *Journal of Obstetrics and Gynaecology Canada* 42, 5 (May 2020), 583–590. https://doi.org/10.1016/j.jogc.2019.09.023 Publisher: Elsevier.