Hacking Women's Health

Madeline Balaam

Open Lab

Newcastle University, UK

Madeline.balaam@ncl.ac.uk

Lone Koefoed Hansen

Dept of Digital Design and
Information Studies

Aarhus University

koefoed@cavi.au.dk

Catherine D'Ignazio

Emerson Engagement Lab

Emerson College

catherine_dignazio@emerson.edu

Emma Simpson

Open Lab

Newcastle university, UK

emma.simpson@ncl.ac.uk

Teresa Almeida

Open Lab

Newcastle University, UK

teresa.almeida@ncl.ac.uk

Stacey Kuznetsov

School of Arts, Media, and
Engineering

Arizona State University

kstace@asu.edu

Mike Catt

Institute of Neuroscience

Newcastle University, UK

michael.catt@ncl.ac.uk

Marie L.J Søndergaard

Dept of Digital Design and
Information Studies

Aarhus University

mljuul@cavi.au.dk

Abstract

The aim of this two-day workshop is to bring together a nascent community of researchers to share research, ideas, methods and tools that can encourage, inspire and strengthen those of us working on digital women's health. Our workshop aims to take a pro-active stance, offering participants the opportunity to critique, design and hack existing and new women's digital health experiences. Or, in other words, to get their hands dirty. Through our hack-led event work we aim to face head-on issues related to digital women's health, such as taboo, power and prejudice. This workshop will address current gaps in research and practice by enabling us to develop the confidence, networks and strategies that can facilitate researchers / designers / technologists to work within this space.

Author Keywords

Women's health; digital technology; intimate care; taboo

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; See http://acm.org/about/class/1998 for the full list of ACM classifiers. This section is required.

Background

In HCI there is nascent body of research investigating technology in relation to women's health. Within this, we are seeing several categories of research emerging: from reproductive health and the experiences of

motherhood; self-tracking and learning to know the female body; to how women might use technology to explore their sexuality.

For example, there is a wealth of research exploring tools to support healthcare record management across pregnancy [5], and mobile tools to encourage healthy behaviours in pregnant women [13,17]. In addition, there is a body of work focused on upskilling and supporting midwives and health workers in developing countries [18,25]. A smaller volume of work has explored other elements of women's health, for example, the development of an mHealth platform to support women going through the menopause [30] and the exploration of mobile applications for reminding women to take their contraceptive pill [23]. Other work has explored the specific needs of women with breast cancer in the development of online social support systems [21], as well as tools for monitoring the systems of women with breast cancer in rural settings [10]. Systems for gynecologic exam training have been explored in [15] suggesting that medical students can learn both procedure and diagnose from interacting in a virtual environment.

Rarely do these devices and technologies situate themselves within the 'dirty work' of women's health, but on the periphery, offering advice about how to be healthy, or how to recognise labor, as well as easing the burden of sharing health records between healthcare providers. Labella is an exception to this [1] providing an encounter for women to learn about their intimate bodies, while the speculative design project Menstruation Machine offers an embodied experience of what it means to menstruate, questioning gender essentialism associated with the physiological

experiences of man and women [22]. In a similar vein, Mommy Tummy [12] provides an embodied experience of pregnancy enabling anyone to experience this typically womanly experience, from those desiring to become pregnant, through the transgendered women.

We have also witnessed community and commercial projects and products dealing with the sexuality of women, either as an empowering connection like the Lick This app [2], the Hacking my Vagina sex-toy hack [20], or the DIY Gynecology laboratory GynePunk [8]. In addition, we see experiments by young female designers addressing the female body and the sexuality of women [9,24], while at the same time the data from the female body is collected and commercialised in projects like LoonCup [14], the Bellabeat Leaf [4]. The recently available wireless vibrator We-Vibe [26], for example, caused quite a scandal when it became clear that the company stores the use-data of this IoT sex toy. Some projects also reflect the darker side of women's lived sexual experiences, such as the friendship bracelet ONEE marketed as a buddy system for women who end up in uncomfortable situations with men [16]

Designing for the female body and women's health is troublesome. The female body as a site for research is claimed as taboo [19]. Research through design has been offered as one possible avenue through which contradictions and 'immodest' proposals might be examined [3], similarly humour has been noted as an approach to design which can be applied to overcome the taboo of the female body [1]. Finally, [11] highlight the use of 'hacking' and social media engagement as a means of critiquing and re-envisioning women's health technologies.

With this workshop we seek to bring together an emerging community of researchers to tackle issues relating to digital technologies and women's health, the female body, as well as 'hack' existing troublesome examples. We seek researchers from all backgrounds to join us in this attempt to revolutionise research in this area, and innovate on available options for women worldwide. We anticipate the workshop will cover a range of key themes, including:

Women-Centred Design: How can designers of systems for women's health put women's voices and experiences at the center of the design process? Practically, we can think about this question in terms of the methods and approaches that can be best put to work to understand and resolve issues in relation to women-centred design. Are there methods to utilize and/or adapt from Feminist HCI, Participatory Design and Human Centered Design, or perhaps from the arts?

Feminist Technologies, Hacking and Making: What happens when we frame the act of hacking or making as feminist? How has the hacking culture historically and culturally included and excluded women's voices? [7] Is it possible for us to hack not only the existing technologies but also the policy structures, workplace conditions and social stigma around women's health? Thus, we refer to 'hacking' as a literal, a political, as well as a figurative level. Here, we seek to build in particular on the CHI 2016 [6] 'Exploring Social Justice, Design, and HCI' workshop, by asking whether health technologies can become a site for the empowerment of women?

Feminist Speculative Design: How do different technologies configure and re-configure the female body and question the gender binary? What kinds of sociotechnical systems do these technologies sit within? How can we envision futures of women's health outside the normalized understandings of the female body? Can we use design as a means to discuss women's health as aspects of gender and sexuality in HCI? More conceptually, we can begin to think about gender assumptions, and whether when we say the female body, we mean simply cisgender women, or technologies that might be used by men, other genders, whole families or communities?

Organisers

Madeline Balaam is a lecturer in Interaction Design at Newcastle University. She has spent the last five years researching issues related to women's health, starting with a CHI 2013 workshop on 'Motherhood and HCI', which was closely followed by the release of a mobile application, FeedFinder, supporting women in breastfeeding in public. Madeline is particularly interested in how digital technologies provide opportunities to advocate for new forms of women's health experiences. Madeline leads a number of projects seeking to innovate in women's health, including the design and development of a mobile phone based fertility tracker specifically for developing regions.

Lone Koefoed Hansen is an associate professor at Aarhus University. She works at the intersections of art, design, cultural theory, and computing and has worked with feminist design, critical computing, participatory it, and with how technology, art, and culture are interwoven in our everyday lives.

Catherine D'Ignazio is an Assistant Professor of Data Visualization and Civic Media at Emerson College. She is a researcher, artist and software developer. Her work focuses on data literacy, media innovation and civic art. Recently she has run a breastpump hack, which sought to raise awareness of the experiential, social and political realities of breastfeeding and pumping milk. The hack inspired many women to share their experiences with the breastpump, and encouraged commercial suppliers to reflect on their machinery.

Teresa Almeida has just submitted her PhD on intimate care practices in women's health. Teresa is interested in feminism, gender and design, and has a wealth of experience designing technology for women, with women. In particular, Teresa has investigated women's understanding of their intimate anatomy using a range of design and craft techniques. These explorations have resulted in award-winning design, where Teresa has evidenced the role that digital can play in support intimate bodily knowledge.

Emma Simpson is an EPSRC funded Digital Civics PhD candidate at Open Lab, Newcastle. Her research is situated at the intersection of Public Health and HCI. Recent work and publications are centred around understanding the role of FeedFinder in breastfeeding practice, across both public and professional settings.

Stacey Kuznetsov is an Assistant Professor at the School of Arts, Media, and Engineering (AME) with a joint appointment at the School of Computing, Informatics, and Decision Systems Engineering (CIDSE) at Arizona State University. Her research explores the role of technology in collective efforts to construct knowledge and address issues. She is interested in low-cost tools and hands-on making for citizen science, community activism, and (DIY)biology.

Mike Catt is a Professor of Practice in Health Technologies in the Institute of Neuroscience and Newcastle University. Prior to joining the University Mike worked for a range of pharmaceutical companies designing and developing pregnancy and fertility tests for women. Mike is interested in how these existing technologies can be improved through the application of 'smart' design.

Marie Louise Juul Søndergaard is a PhD candidate at Aarhus University, working interdisciplinary in the intersection of HCI, art, and design. Her research examines critical and feminist design of intimate technologies. From an experimental design approach she design internet-connected panties that questions aspects of gender and sexuality in the future of IoT

Website

A workshop website will be hosted at: www.openlab.ac.uk/hwh. In the run-up to the workshop we will use the website to provide a place to discuss the workshop and its goals with participants. This will be achieved through the use of blogs, discussion forums and a twitter feed, including using a twitter# where participants (and others) can post relevant examples and discussions. Following the workshop, the website will become a living document of the work of the community and field within the context of digital women's health and feminist HCI. In essence, we will be seeking to create a home for researchers undertaking this kind of work, including biographies of researchers working in the area, a growing bibliography

of important texts and a discussion forum for ongoing interaction between researchers.

Pre-Workshop Plans

The 'call for participation' will be distributed through the social media accounts of the organisers, across a range of relevant mailing lists, and direct emails will be sent to members of the community who showed an interest in relation to informal discussions of the workshop at CHI 2016 and similar venues.

Between February and May we will work with attendees to shape the focus of our workshop (specific phase of women's health, specific technology or digital experience), identifying technologies and subjects within women's health which participants are most motivated to 'hack'. As areas emerge we will co-create a shared reading list (comprising texts as well as examples and cases) to help attendees engage with the workshop's topics prior to the event. A significant component of our pre-workshop plan is to nurture the community of interested researchers to become inspired and gain momentum for working in this area.

Based on D'Ignazio's successful use of social media (Facebook) as a means of soliciting user experience of the breastpump, we similarly will utilize social media to initiate a conversation with women outside of the community around the technologies and subjects that our participants would most like to hack. Pre-workshop activity will include appointment of a social media chair, whose role will be to increase outreach and publicise while encouraging the generation and collection of resources (from social media and traditional media). Women are heavy users of social media platforms like Facebook, Instagram, Pinterest, etc, and so these will

be relevant platforms to engage in. The data thus collected will be brought to the workshop to inspire and drive the direction of our hack event.

We will have a number of key questions which will guide the focus of our discussions pre-workshop, for example, 'what is feminist tech?', 'how do we design for inclusiveness?', 'what does it mean to design for women? Is it different than other design processes?', 'what are the barriers (and stigma?) for working in this domain', what are the issues relating to privacy and access?', 'how do we reach out to feminist groups beyond CHI? And what are other modes of dissemination?' and further exploration of feminist makerspaces/hacker culture.

Using our website as a central hub, we will collate resources which will be used in our hack event, while identifying materials and technologies that we plan to hack in the event. We expect that the data collected from social media and news channels will be part of the workshop.

Workshop Structure

This two-day workshop aims to develop a unique community around women's health technologies within HCI. This will be achieved through discussions, confessions, hands-on critiques, followed by design and hacking activities, where we seek to re-think and re-imagine women's health technologies. We intend these hacking activities to help identify fruitful avenues for future research, as well as establish colleagues with whom to take action. Our hack will consist of two separate days and not run through the night.

Day 1 will begin with an introductory session and pitch from key topic/theme leads identified in the pre-workshop discussions. Post-pitch, we will encourage workshop attendees to join their group of interest and begin the 'hack'. The hacking activities will continue for the remainder of the two days but we will check-in at regular intervals, with each group presenting their work-in-progress thus far and obtain constructive feedback from the rest of the workshop attendees. In addition, we will revisit the data we collected from social media and confirm we are addressing issues relevant to the lived experiences of women. At these stages of the hack, we will also provide an opportunity for workshop attendees to switch to another group in order to maximize skill sharing. Taking a project based learning approach - reflecting, obtaining and providing constructive feedback will ensure that workshop attendees foster a deeper learning experience. The plan proceeds:

9:00 – 11:00 (Coffee break) Welcome and introductory session. Workshop attendees give a 'lightening' introduction – including background and their position in relation to women's health and feminist HCI. We will revisit and recap the chosen topics and themes identified in our pre-workshop activities.

Pitch – a 5-minute pitch from each of the pre-selected topics/themes. Workshop attendees join their chosen group of interest and begin hacking activities.

Post lunch – Hacking!

15:00- 15:30 Check-in, give and receive feedback and critique how the hack addresses the lived experiences collected through social media channels.

Proceed with hacking activities until end of the day.

Evening – social event over dinner, providing an opportunity for further networking, sharing ideas and reflection on Day 1.

Day 2 will continue with the hacking activities. We will check-in at 11:00 with each group presenting their work-in-progress, give and recieve feedback from the rest of the group and critique their artifacts against the social media data. Following this, we will continue hacking activities, pre and post lunch until we have a formal presentation of artifacts midafternoon. Together, we will co-develop an agenda for taking the research forward and pledge commitment to action points. Day 2 will close with an informal evening social event.

Post-Workshop Plans

We will follow the workshop with several engagement and dissemination activities. First, we will focus on scaffolding a feminist HCI community within the immediate CHI conference and its attendees. To this end, the artifacts created during our event will be showcased at the main conference along with posters that highlight key takeaways. Second, we will ensure that discussion and resource sharing continues amongst workshop attendees and other interested parties beyond the CHI event. Media content created during the workshop will be shared on the workshop website and a persistent mailing list will support future collaborations. Finally, we will report on our workshop activities and findings to the wider HCI community. Our broader dissemination will include a submission to the ACM interactions magazine outlining the shared goals and outcomes from the workshop; a special issue of a leading HCI journal to share workshop participants'

research. In addition, we will engage broader audiences in our work through other formats such as zines and podcasts.

Call for Participation

In HCI there is growing body of research investigating technology in relation to women's health and feminist HCI. Such work covers a wide range of topics and themes pertinent to the empowerment of women, however, there is a lack of unity and representation of a community within HCI. We wish to draw together this community of researchers, as well as others interested in the area, to legitimize and encourage research in this currently overlooked area.

We invite interested candidates to submit a 2-page position paper in CHI Extended Abstracts format or 2-minute video pitch that describes the author's experience engaging with a specific theme, or challenge involved with designing for, using, or evaluating technologies that relate to the context or experience of women's health and feminist HCI. Please include a short biography and relevant skills you can contribute to our hack event. We are seeking to cultivate a unique group of researchers therefore we positively encourage submissions from a diverse range of disciplines and perspectives. Submissions will be selected based on their originality, quality and ability to provide a valuable contribution to the community. There are two deadlines – early bird 21 December 2016 and final submission deadline 24 February 2017. Submit your position paper or pitch directly to madeline.balaam@newcastle.ac.uk. We require that at least one author of each accepted position paper must attend the workshop and that all participants must register for both the workshop and for at least one day of the conference.

You can access our website here: www.openlab.ac.uk/hwh

References

1. Teresa Almeida, Rob Comber, Gavin Wood, Dean Saraf, and Madeline Balaam. 2016. On Looking at the Vagina through Labella. In *In Proc. CHI '16*.

2. Lick This App. Lick This App. Retrieved October 12, 2016 from http://lickthisapp.com

3. Jeffrey Bardzell, Shaowen Bardzell, and Lone Koefoed Hansen. 2015. Immodest Proposals: Research Through Design and Knowledge. In *CHI 2015*, 2093–2102.

4. Bellabeat. Bellabeat Leaf. Retrieved October 12, 2016 from https://webshop.bellabeat.com/pages/period

5. Henrik Enquist and Konrad Tollmar. 2008. The Memory Stone ± A Personal ICT Device in Health Care. *Memory*: 18–22.

6. Sarah Fox, Mariam Asad, Katherine Lo, Jill P. Dimond, Lynn S. Dombrowski, and Shaowen . Bardzell. Exploring Social Justice, Design, and HCI. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '16).*, 3293–3300. http://doi.org/http://dx.doi.org/10.1145/2851581.2856465

7. Sarah Fox, Rachel Rose Ulgado, and Daniela Rosner. Hacking Culture, Not Devices: Access and Recognition in Feminist Hackerspaces. In *In Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW '15).*, 56–68. http://doi.org/http://dx.doi.org/10.1145/2675133.2675223

8. Gynepunk. Gynepunk. Retrieved October 12, 2016 from http://gynepunk.tumblr.com

9. Marie Louise Søndergaard Hansen and Lone Koefoed. PeriodShare: A Bloody Design Fiction. In

In Proc. NordiCHI 2016 Extended Abstract.

10. Md Haque, Ferdaus Kawsar, Mohammad Adibuzzaman, et al. Findings of e-ESAS: a mobile based symptom monitoring system for breast cancer patients in rural Bangladesh. In *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*, 899–908.

11. Catherine D Ignazio, Alexis Hope, Becky Michelson, Robyn Churchill, and E 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 *In Proc. CHI*.

12. Takayuki Kosaka, Hajime Misumi, Takuya Iwamoto, Robert Songer, and Junichi Akita. 2011. "Mommy Tummy" a pregnancy experience system simulating fetal movement. In *SIGGRAPH 2011*, Article 10. http://doi.org/10.1145/2048259.2048269

13. N Kumar and J. Richard Anderson. 2015. Mobile Phones for Maternal Health in Rural India. In *In Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems (CHI '15)*, 427–436. http://doi.org/DOI: http://dx.doi.org/10.1145/2702123.2702258

14. LoonLab. LoonCup. Retrieved October 12, 2016 from https://www.kickstarter.com/projects/700989404/looncup-the-worlds-first-smart-menstrual-cup

15. Ronei M Moraes, Daniel F L Souza, Milane C O Valdek, and Liliane S Machado. 2006. A Virtual Reality Based Simulator for Gynecologic Exam Training. In *Information Technology Based Higher Education and Training (ITHET '06)*, 786–791. http://doi.org/10.1109/ITHE

16. Onee. No Sister Left Behind. Retrieved October 12, 2016 from https://wearonee.com

17. Tamara Peyton, Erika Poole, Madhu Reddy, Jennifer Kraschnewski, and Cynthia Chuang. 2014. "Every pregnancy is different": designing mHealth for the pregnancy ecology. In *In Proceedings of the 2014 conference on Designing interactive systems (DIS '14).*, 577–586. http://doi.org/DOI: http://dx.doi.org/10.1145/2598510.2598572

18. Divya Ramachandran, Vivek Goswami, and John Canny. 2010. Research and reality: using mobile messages to promote maternal health in rural India. In *4th ACM/IEEE International Conference on Information and Communication Technologies and Development (ICTD '10)*.

19. Jennifer Stroud Rossmann. 2008. Built to Spec ? The vaginal speculum as a case study of inadequate design. *Ambidextrous*: 47–49.

20. M Scott. Hacking my Vagina. Retrieved October 12, 2016 from http://scanlime.org/2012/11/hacking-my-vagina/

21. Meredith M Skeels, Kenton T Unruh, Christopher Powell, and Wanda Pratt. 2010. Catalyzing Social Support for Breast Cancer Patients. In *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '10)*, 173–182. http://doi.org/10.1145/1753326.1753353

22. Sputniko! Menstruation Machine. Retrieved October 12, 2016 from http://sputniko.com/2010/07/menstruation-machine-takashis-take/

23. Katarzyna Stawarz, Anna L Cox, and Ann Blandford. 2014. Don ' t Forget Your Pill ! Designing Effective Medication Reminder Apps That Support Users ' Daily Routines. 2269–2278.

24. Cristine Sundbom, Anne-Christine Hertz, Karin Ehrnberger, and Emma Börjesson. The Andro Chair, designing the unthinkable: Men's right to women's experience in gynaecology. In *In Proc. Nordes 2013: Experiments in Design Research*.

25. Heather Underwood, S. Revi Sterling, and John Bennett. The PartoPen in practice: evaluating the impact of digital pen technology on maternal health in Kenya. In *Sixth International Conference on Information and Communication Technologies and Development (ICTD '13)*, 274–283.

26. We Vibe. We Vibe Plus. Retrieved October 12, 2016 from http://we-vibe.com/we-vibe-4-plus