PARTICIPATORY RESEARCH METHODS FOR INVESTIGATING DIGITAL HEALTH LITERACY IN CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITIES

RUTH DE SOUZA, DANNY BUTT, SUNEEL JETHANI AND CHRIS MARMO

CORRESPONDING AUTHOR: RUTH DE SOUZA, VICE-CHANCELLOR'S RESEARCH FELLOW SCHOOL OF ART, COLLEGE OF DESIGN AND SOCIAL CONTEXT, RMIT UNIVERSITY MELBOURNE, AUSTRALIA. EMAIL: RUTH.DESOUZA@RMIT.EDU.AU

KEYWORDS

ABSTRACT

DIGITAL TECHNOLOGIES AND PRE/PERI-NATAL APPS ARE TRANSFORMING MATERNITY CARE AS WOMEN USE COMMUNICATIONS TECHNOLOGIES TO OBTAIN INFORMATION AND SUPPORT. WOMEN FROM CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) BACKGROUNDS EXPERIENCE INFORMATION AND SUPPORT GAPS, HOWEVER, RESEARCH ON NEW HEALTH COMMUNICATIONS HAS RARELY ENGAGED WITH THIS GROUP, RAISING CONCERNS ABOUT THE APPLICABILITY OF THESE TECHNOLOGIES WITH HIGHLY DIVERSE COMMUNITIES. THE GOAL OF THIS PILOT STUDY LOCATED IN IN NORTH RICHMOND, A CULTURALLY DIVERSE NEIGHBOURHOOD OF MELBOURNE, WAS TO TEST THE VALUE OF "DESIGN PROBES" IN ENGAGING WOMEN FROM CALD BACKGROUNDS IN DISCUSSIONS ABOUT HEALTH TRACKING AND WEARABLE HEALTH TECHNOLOGIES IN THE CONTEXT OF PREGNANCY AND PARENTING. THIS STUDY FOUND THAT DESIGN PROBES WERE EFFECTIVE IN ENABLING PARTICIPANTS TO PARTICIPATE IN EXTENDED DISCUSSIONS ON THE IMPLICATIONS OF DIGITAL HEALTH TECHNOLOGIES. PARTICIPANTS WERE AWARE OF THE WAYS THAT HEALTH INFORMATION SERVED THE NEEDS OF MULTIPLE ENTITIES, AND SOUGHT MORE CONTROL OVER WHERE AND WITH WHOM THEIR DATA WAS SHARED WITH.

AUTHOR BIOGRAPHIES

DR. RUTH DE SOUZA

RUTH.DESOUZA@RMIT.EDU.AU ORCID ID: ORCID.ORG/0000-0003-3862-5375 IS A VICE-CHANCELLOR'S FELLOW AT RMIT UNIVERSITY IN MELBOURNE, BASED IN THE SCHOOL OF ART. SHE IS A NURSE, ACADEMIC AND A COMMUNITY-ENGAGED RESEARCHER IN GENDER, RACE, HEALTH AND DIGITAL TECHNOLOGIES. RUTH'S RESEARCH IS PARTICULARLY CONCERNED WITH USING ARTISTIC AND DESIGN METHODS IN HEALTH RESEARCH TO TRANSFORM INEQUITIES.

DR. DANNY BUTT

DANNY.BUTT@UNIMELB.EDU.AU ORCID ID: ORCID.ORG/0000-0002-6229-9525 IS SENIOR LECTURER IN INTERDISCIPLINARY PRACTICE AND ASSOCIATE DIRECTOR (RESEARCH) AT THE VICTORIAN COLLEGE OF THE ARTS, UNIVERSITY OF MELBOURNE, WHERE HE CONVENES PROGRAMMES IN SOCIAL PRACTICE AND GRADUATE RESEARCH IN THE PHD AND MFA PROGRAMMES. HIS BOOK ARTISTIC RESEARCH IN THE FUTURE ACADEMY WAS PUBLISHED BY INTELLECT/UNIVERSITY OF CHICAGO PRESS IN 2017.

SUNEEL JETHANI

SUNEEL.JETHANI@UTS.EDU.AU ORCID.ORG/0000-0003-2134-0904 IS A RESEARCHER AND LECTURER AT THE UNIVERSITY OF TECHNOLOGY SYDNEY. HIS RESEARCH CENTRES ON EMBODIED TECHNOLOGY, DATAFICATION AND ISSUES OF TECHNOLOGY GOVERNANCE AND DESIGN. SUNEEL HAS PUBLISHED IN INTERNATIONAL COMMUNICATION GAZETTE, COMMUNICATION, POLITICS AND CULTURE, M/C JOURNAL AND IN EMBODIED COMPUTING (2020) MIT PRESS. SUNEEL HAS FORTHCOMING BOOKS ON SELF-TRACKING TECHNOLOGY (EMERALD, 2021) AND OPEN DATA (PALGRAVE, 2021).

DR. CHRIS MARMO

CHRIS@PAPERGIANT.NET IS CO-FOUNDER AND CEO OF AUSTRALIAN-BASED DESIGN AND RESEARCH CONSULTANCY PAPER GIANT. FOUNDED IN 2013, PAPER GIANT WORKS INTERNATIONALLY WITH DIVERSE CLIENTS IN THE PUBLIC AND PRIVATE SECTORS. HIS RESEARCH INTERESTS INTERSECT DESIGN, ANTHROPOLOGY AND DIGITAL ETHNOGRAPHY.

Introduction

Contemporary life is marked by an "intensive infiltration of networked wireless technologies and digital mobile devices" (Ajana, 2017, p. 1) making it easy for people to routinely track, monitor, collate and analyse their health/health data, and also for private corporations to access that data. Tracking health indicators allows individuals to set goals, monitor their health and identify potential changes to enhance fitness and health in the absence of a health professional. The proliferation of tracking technologies challenges distinctions between patient and consumer; device and data; health care and wellness; and medical data and the commercialisation of health (Rich & Miah, 2017).

Technological availability meets consumer agency to increase interest in flexible access to personal health information, or even self-management of health information. The idea of the electronic health record has historically pointed to a central repository for clinically generated health information which can be viewed by patients and their clinicians. In Australia, for example, the government's My Health Record system is a digital health record system containing online summaries of health information such as medication, allergies and treatment. Provider supplied records not only aid the completeness of data but can also directly improve the quality of the relationship between consumers and providers through increasing trust and communication (Frost & Massagli, 2008). However, at present there is no mechanism for consumer applications to supply data to the My Health Record system, and as many popular apps are developed in the United States, they have no specific requirement or motivation to interface with other governments' health systems, even if this were possible. Therefore, we can see the market-based availability of health related technologies proposes a new regime of governance which evades historical modes of state-managed health promotion, requiring new approaches to how equity and effective participation can be fostered, particularly for marginalised populations.

Health Literacy and Participation

The promise of technology-driven health participation is articulated by the MIT Media Lab's New Media Medicine group in their Manifesto, where they note that the market failures of contemporary medicine result in "[c]osts skyrocketing, health outcomes [being] uneven, and the patient experience too often [being] unacceptable." They attribute these problems to:

> the historical inequality between medical experts and health-care professionals (particularly doctors) and patients. This inequality has been based on information asymmetry: only experts could access medical information and use it to conduct medical research, make diagnoses, and develop treatments. The Internet has all but destroyed this information asymmetry, but the inequality remains (Moss, 2008, p. 1).

The question of how personally shared information about physical activities and biodata articulate to shared decision making in a healthcare setting is a vexed one. Among the many concerns about self-tracking are questions about health literacy in an age of ubiquitous health technology, and in particular, the potential of self-tracking technologies to alienate and (re)produce inequalities. Health literacy implies a capacity to act on health information in order to enhance one's quality of life, but self-tracking as a mode of personal data production can be conceptualised as being both system and user driven (Vamos & Klein, 2016). Effective "consumer participation" in the governance of health data in this ecosystem is typically restricted by design, as the relevant sorting and decision-making is "black boxed" in the design of applications and interfaces (Galloway, 2012; Pasquale, 2015). The capacities of data to be transacted between parties lies in the etymology of the word data itself. In Latin, that which is *being given*; in French, that which leaves *an empirical trace*. The processes which bring about the modulation of these two states (Galloway, 2012), in the case of technologies that garner personal health data, are obscured from users – who are also the subjects of the data – firstly in the institutional protocols of the healthcare profession and then in the technical logic that governs the information processing and management in the device and its associated analytical platforms.

In the digital health context, therefore, while health literacy as access to generic medical information may no longer be as asymmetrical, the alternate modes of information governance in consumer-oriented apps require users to be much more proactive in their speculative thinking about potential use of their information. One specific concern is whether existing legal, ethical and social norms can ensure security and privacy in a big data world, given the decreased cost and increased

technological ability to "capture, aggregate, and process an ever-greater volume, velocity, and variety of data" (Executive Office of the President, 2014, p. 2). App-collected data may resemble that collated in a medical context but are not subject to the same privacy regulations as in a health-care setting. Unauthorised third party access is a key issue for many stakeholders outside the clinical scene, such as governments, private organisations (including insurance companies), employers and police (Segura Anaya et al., 2017). Nissenbaum (2016) notes, for example, that employers have inappropriately become recipients of self-tracking information, as their expanded roles encompassing benefit provision, insurance and workplace wellness, extending their reach into areas of health data which were historically reserved for friends, family and external care providers. Furthermore, self-tracking data often reside on platforms that are often out of the jurisdiction of the nation where the user is located (Segura Anaya et al., 2017). There is a need to extend digital health literacy in both consumer and developer communities through increased awareness of consumer preferences around issues of accessibility, equity and the risks associated with the production, archiving and sharing of personal health data.

Maternity and Self-tracking

The desire to reduce information asymmetry is notable in pregnant women, who report using the Internet and apps for information because what they receive from antenatal service providers is inadequate (De Souza, 2006; Lupton, 2016; Thomas & Lupton, 2015). The heightened significance of health communication and information-seeking during the perinatal period could be attributed to the uncertainty and anxiety that often accompany pregnancy and early parenthood (Epstein et al., 2017). Quality health information provided through new communication technologies can empower women in pregnancy and parenting by enhancing health literacy and providing mechanisms for self-care (Tripp et al., 2014), facilitating a sense of control and self-efficacy (Carissolii et al., 2016) and "peace of mind" (Lupton, 2016). Thus, digital technologies and pre/peri-natal apps are transforming maternity care as women use communications technologies to share scans, seek alternate opinions and connect to communities of support via social media, Skype, FaceTime and WhatsApp (Pezaro & Lilley, 2015).

In maternity, devices and apps produce (self-)knowledge of the pregnant body where women are encouraged to evaluate themselves according to prenatal norms, and consequently take up self-care practices of active health, lifestyle, self-assessment and self-education (Johnson, 2014). At the time this research was undertaken, a search of Apple's app store for "pregnancy" returned about twenty products that were available for the iOS platform. These applications range from informational resources for midwives, obstetricians, GPs and patients that provide information on optimal times for performing an amniocentesis or chorionic villus sampling and maternal plasma DNA testing; calculating estimated gestational age (EGA), estimated fetal weight, and estimated date of delivery (EDD). Other apps are designed for providing information on fitness during pregnancy, menstrual tracking, and some are even designed for use with babies to encourage hand-eye coordination, such as *Baby View*.

Data garnered through self-tracking practices can facilitate more participatory and preventative approaches to healthcare for mothers, enhancing decision-making by providing benchmarks for health indicators with the wider population (Ajana, 2017). Personalised data automatically generated by wearable devices – about mothers themselves, their foetuses and infants – can be shared through social networks (Lupton, 2016), providing an entirely new context for maternal health literacy, where constant feedback loops of customised information can be monitored and distributed with limited clinician involvement. There is scant data on the extent to which the use of maternity apps in the perinatal period improves care, although there is research that suggests that 'activated' or health literate patients get more support (Ledford et al., 2016), suggesting that digital health information plays a role in activating not only the user, but also the maternal health system.

Concerns about the standards and security of health apps were found to be warranted in a study examining the trustworthiness of ten of the most popular, free child health apps on the Apple iOS and Google Android operating platforms. Using four criteria (health professional involvement, evidence-based medical practices, functional requirements, and usability and security), Scott et al. (2015) found that none of the selected mobile child health apps were fully functional, usable or secure; and only two of the 10 apps were fully functional and usable, but they neglected to meet security requirements. The two apps that i) met functional and security tests, and ii) involved health professionals and evidence-based medical content were not fully usable. Lupton and Pederson (2016) found few concerns about the privacy or security of personal data in a survey of Australian women, theorising that privacy concerns were sacrificed in the interests of being able to receive customised information. These

findings are borne out in a 2009 study which found moderate concerns about privacy, but these risks to privacy were considered pragmatically unavoidable as part of receiving information (Weitzman et al., 2009).

Culturally and linguistically diverse mothers

Women from culturally and linguistically diverse (CALD) backgrounds are more likely than non-CALD women to experience suboptimal and culturally unsafe care in pregnancy. In an era of 'choice', 50% of CALD women were not given the choice to use an interpreter, or choose the gender of their care provider (Mander & Miller, 2016). For CALD women, communication issues with care providers and not knowing what to ask and how to seek health information and assistance are also significant (Yelland et al., 2015). There is a clear need for health services to respond to ethnic/cultural diversity and disadvantage in terms of pregnancy, childbirth and post-partum care (McMichael et al., 2014). Women from CALD backgrounds experience information and support gaps (De Souza, 2005; De Souza, 2006), yet, despite evidence of challenges to health literacy in CALD communities (Australian Bureau of Statistics, 2006), research on new health communications has only recently begun to engage with women from CALD backgrounds (Hughson et al., 2018; Smith et al., 2017).

Research about how different groups of women are engaging with maternity apps features mainly highly-educated women who are fluent in English (Lupton & Pedersen, 2016). Concerns about the exclusion of CALD populations and the need for research with specific CALD audiences (Greenstock et al., 2012) are beginning to be rectified (Hughson et al., 2018; Smith et al., 2017), noting that many mobile media platforms are easily customisable for different language groups, potentially aiding digital health literacy for CALD women. However, cultural safety is understood to be not only a matter of transliteration, but also responsiveness to different social structures that we indicate with the shorthand term "culture". Maternity is a site where differences understood as cultural are given powerful expression, particularly when meeting a historically European health system (De Souza, 2008; Spivak, 2006).

There is concern about the quality, health literacy and the cultural and linguistic appropriateness of health-related applications that change people's attitudes and behaviours through "mobile persuasion" (Tirado, 2011). Most mobile health (mHealth) programmes are designed in one of two ways: 1) with an imagined ideal service user that Paasche-Orlow describes as "wealthy, worried and well" (National Academies of Sciences, Engineering, and Medicine et al., 2015), incorporating the cultural assumptions of dominant technology platforms; and 2) with minimal input from target end-users and which are not tailored or personalised (Eyles et al., 2016). Thus, the benefits of technological advances are unevenly distributed if people from CALD backgrounds do not receive health communication that engages with their language, cultural beliefs and idioms of health literacy level. It is critically important to consider questions such as how cultural differences influence how health and health information is managed; how information technology is used in different cultural settings; and how appropriate design can vary for people from different cultural contexts (Valdez et al., 2010).

Aims

This paper has two aims. The first is to contribute to the growing evidence base in using design principles in participatory health research, specifically in methods and tools for making 'things' that can describe future objects, concerns or opportunities (Sanders & Stappers, 2014). The other is to share findings of a qualitative pilot study about how self-tracking technology is perceived by women from CALD backgrounds in the perinatal period. The goal of the study was to explore how best to engage this user group in a discussion about health tracking, in order to ascertain their current use and potential use of wearable health technologies. We also report on our use of "design probes" in research to explore and better understand CALD background women's perspectives regarding consumer health technologies in the context of pregnancy and parenting.

In this paper we present findings from a workshop that both confirm and question our *a priori* assumptions drawn from the literature above; and we also outline the ways in which we are adjusting our ongoing research in light of these findings. As our literature review found few methodological leads on how to conduct research on health technology with CALD women, our hope is that this report will be beneficial to others undertaking qualitative health research with CALD communities and CALD women in particular.

Methodology

The rise of design methods asks researchers to not simply accept existing technological solutions, but to imagine new ones, and therefore a range of methods associated with "co-design" have focused on ways to facilitate the transformation of experience into product (Sanders & Stappers, 2014). Research interventions such as providing probe packages; having participants answer ambiguous questions creatively or engaging with generative toolkits; or having participants create and evaluate prototypes made by designers are common strategies.

According to Gaver et al. (1999), probes can be used as a method to capture information about a specific group through intentionally facilitating unexpected ideas and as an attempt to challenge more rationalist methods and explore tools that would elicit subjective and creative responses rather than objective ones . They first developed the idea of a "cultural probe" to explore issues of design for older people. Madden et al. (2014) suggest that probes have four main purposes: to inspire design, to gather data, to increase participation and to facilitate dialogue. They can do this because they provide an unobtrusive way of obtaining data and can include materials that assist in self-documentation. The probes support activities that allow creative and subjective responses from users which help them represent their experiences, needs and attitudes (Tsvyatkova & Storni, n.d.). In Gaver et al.'s influential work, the designers outline the elements of their methodology:

> "We approach research into new technologies from the traditions of artist–designers rather than the more typical science- and engineering-based approaches. Unlike much research, we don't emphasize precise analyses or carefully controlled methodologies; instead, we concentrate on aesthetic control, the cultural implications of our designs, and ways to open new spaces for design. Scientific theories may be one source of inspiration for us, but so are more informal analyses, chance observations, the popular press, and other such "unscientific" sources." (Gaver et al., 1999, p. 24).

Setting, Recruitment and Participants

For this pilot study, recruitment took place at venues around the Richmond Public Housing Estate in North Richmond, including the health centre and local playgroups. North Richmond is a culturally diverse neighbourhood of Melbourne, comprising a high percentage of overseas-born residents (38%). Less than half of the North Richmond population was born in Australia (48.4%). The main overseas countries of origin are Vietnam (12.3%), East Timor (4.6%) and China (3%). One third of North Richmond residents are from non-English speaking backgrounds (32.4%) (City of Yarra, 2011).

Eligible participants were CALD background women who had had a baby within the last twelve months or were currently pregnant. Posters in English inviting women to a focus group where they could learn about how their phone could assist them with maintaining health during pregnancy were placed throughout the Richmond Public Housing Estate, the North Richmond Community Health Centre and City of Yarra Maternal and Child Health services. Only one participant was obtained through the posters. Presentations were also given at two playgroup facilities which yielded subsequent interested parties. Women meeting the eligibility criteria were given an information sheet and were subsequently contacted by telephone to arrange an appropriate time for the focus group. Our recruitment efforts yielded 5 women participants aged between 32 and 38 from South Sudan, Ethiopia, China (via NZ) and Vietnam. The small sample was typical for the research setting and what participants would have been used to at the Centre when discussing reproduction and intimate health issues. In terms of validity, the study was not attempting to develop claims about how different ethnic groups were behaving but to explore which methodological innovations CALD-background women responded to in our research. Participants were invited to attend a two-hour workshop, and those who attended were provided with a grocery shopping voucher for their time.

Ethics

Ethics approval was obtained from the University of Melbourne (1647999.1). Written informed consent was obtained from participants, following verbal explanations of the goals, benefits, and risks of research by volunteers. An interpreter was made

available for one of the participants and provided an explanation. In order to maintain privacy and confidentiality, research participants have been de-identified in transcripts and supplied with a pseudonym in this text.

Workshop

A qualitative exploratory study was conducted in the form of a workshop comprising three activities. These were: a drawing 'warm up'; a teaching session; and an exercise with semi-structured interview questions related to a design probe. The workshop was conducted in English with a Vietnamese interpreter present and childcare was made available to all participants.

Activity One: Warm up

As an ice-breaker, group members were asked to draw an object that they never left their house without. They were invited to share their drawing with the woman next to them and then their new friend was asked to introduce them and their drawing. This part of the workshop brought discussions on digital technology (specifically mobile phone) ownership and usage (Internet access, social media and health apps).

Activity Two: Teaching session

The drawing session was followed by an educational session about three free apps that could be used to promote/facilitate well-being for mothers or pregnant women. A volunteer recently graduated from a Master of Global Media Communication degree facilitated the session, which included Plant Nanny, Lose it and Period Tracker apps. The Plant Nanny app encourages users to drink water while also growing virtual plants. The app lets you choose a cartoon seedling for your virtual window sill. When you drink water through your day, you simultaneously add a glass to your plant on the app. If you remember to hydrate yourself then your plant will also grow. The app also sends notifications to remind you to drink water. The mothers really liked this app, because it helped them to think about remembering to care for themselves. The Lose it app logs meals and tracks calories and provides a way for women to keep track of their eating patterns. Lastly, the Period Tracker app provides a useful way to keep track of when a user's period is due, premenstrual symptoms and overall health trends. This session was enthusiastically received, with women indicating an interest in using them all and suggesting that their networks would also gain value from such educational sessions. Engagement was enhanced from the discussions in the first activity, and this activity was designed to stimulate more detailed conceptual interaction in the final activity.

Activity Three: The "data box" design probe

In the final part of the workshop, each participant was asked to respond to a range of "data boxes" – physical boxes that materialised the abstract concept of personal health data. The Melbourne-based artist Debris Facility was commissioned to provide the data box and proposed a cake box as an everyday object that could "hold" user data – making it relatable to participants. Our data boxes were made from cake boxes by staff at North Richmond Community Health Centre (NRCH) and the research steering group, with a variety of features and aesthetics designed to highlight the wide range of possibilities for a box of one's own health data. The transformation of the "cake" boxes into "data" boxes was facilitated by an artist specialising in the speculative interrogation of wearable embodied technology through the creative appropriation of everyday objects and who provided a range of materials including fabric, paper, sequins etc. to participants. These boxes were chosen by participants during the focus group and transformed using the craft materials into objects representing participants' data stored within a device and then reclaimed at the end of the session for examination by the group. The probes elicited multiple perspectives on this exercise from the participating women and ensured we are able to relate to user actions and perspectives in the co-design activities planned as part of our larger study (Tsvyatkova & Storni, n.d.).

Data analysis and thematic findings

The workshop was audio recorded with participants' permission. After the focus group, volunteers transcribed and cross

checked the recordings of the focus group for accuracy. Then the first author (De Souza) analysed the transcript, using the six steps of thematic analysis detailed by Braun and Clarke (2006) to identify, analyse and report patterns (themes) within data. Three themes emerged from the analysis and are discussed: Using mobile phones to maintain relationships; using phones and apps to self-track; and data sharing with institutions and family.

Using mobile phones to maintain relationships

In the drawing exercise, participants were asked to identify an object they never left home without. All participants identified their mobile phones, in addition to their house keys and wallets (including Medicare card). Participants used their phones for: Social media (especially Facebook); FaceTime; WhatsApp and Viber; phone calls; texts; photos; using the internet to find information related to maternity and parenting; and YouTube to watch media from their home country in their own language. They also used map applications to orientate themselves. These responses highlight how digital communications technologies have transformed the experience of family dispersal, assisting relationships to endure across time and space (Madianou & Miller, 2013; Robertson et al., 2016). Thus, transnational modes of sociality do not require physical proximity, as diverse media and artifacts reshape relationships and make relationship networks seamless and "quasi-continuous" (Baldassar et al., 2016; Robertson et al., 2016).

Self-tracking

In the words of Crawford et al. (2015, p. 494), digital self-tracking devices offer "the promise of agency through mediated self-knowledge, within rhetorics of normative control and becoming one's best self". The linked notions of bodily transformation and potential are manifested through a complex materiality bringing together clinical and phenomenological epistemologies of maternity. The technology used to measure, document and communicate aspects of experiences relating to pregnancy or getting pregnant form a surface through which different types of knowledge are interpreted, contested and evaluated. Many women who participated in our study counted their steps (out of curiosity and to see if they could improve them) or tracked the amount of water they were drinking daily. Initially, when probed these were the only tracked variables identified, but during the education session three women spoke about tracking their menstrual periods and a fourth talked about how she had used a period tracker to plan conception. Much later in the workshop, Nyaluok identified tracking her pregnancy to monitor foetal development, something she had not mentioned earlier:

> Nyaluok: I track my pregnancy development as well...pictures, every week, from 21 and it will tell me at week 21 this is what I expect.

Nyaluok values the gestational age specific information the app provides to her in the form of both a visual image of the foetus, and its pedagogical role in advising her what to expect. Foetal development information provided in apps takes the form of *size* e.g. 'baby is now size of ***, *rate of growth* e.g. baby is growing ***, and *development* e.g. baby can now ***' (O'Donnell et al., 2016). Nyaluok also uses an app for nutrition and exercise:

> Nyaluok: There's an app for pregnancy and nutrition...that food that I take... It tells you every week, when you go to each trimester, they tell you what you need, how much weight you're gonna be putting on, what food you need to have ... and there's an app for pregnancy exercises.

During the last two trimesters of pregnancy, physical and physiological changes become more pronounced and a pregnant woman can gain up to 12.5 kg (29 lbs) during a 40-week pregnancy, with an 8 to 10 inch increase of the waistline (Sohn & Bye, 2015). Apps for maintaining maternal physical well-being include information about healthier food options; exercise; weight gain parameters; vitamin/minerals and supplementation (e.g. iron, calcium, Vitamin D)(O'Donnell et al., 2016). Nyaluok uses the apps for self-disciplining as she follows the authoritative advice of the apps and consumes within suggested guidelines.

Another participant identified the need for greater digital health literacy in the context of the amount of information she could potentially garner:

> *Adeebah: I try only small things but if you track, you're gonna get a lot of information... from the app.*

Adeebah's account highlights the need for improved consumer literacy to be able to sift through the sheer volume of daily personal data (Collins et al., 2012).

Data sharing

These preliminary findings highlight some of the concerns about the sharing of biometric data with different people and organisations.

App users in the perinatal period can become vulnerable, given they enter information about themselves and their foetuses or children which is often intimate and detailed, leaving a digital footprint for a yet to be born infant (Lupton & Pedersen, 2016). In the next part of the workshop, women were asked whether they would be happy to share health information gained through tracking and integrated into a personal electronic health record, with a range of professionals, organisations and family members. The data box acted as a speculative object that allowed the extension of participants' questions and thinking, and the boxes were used by the participants in illuminating their discussion.

Data Sharing with Organisations

Participants were willing to share information in the interests of getting entitlements, but concerned about having control over information that was shared with a third party.

Lien was willing to share information with her employer about general health issues to obtain a sick day, but was not willing to disclose a mental health problem. She was also willing to share information that would facilitate the receipt of a benefit. However, she was concerned about third party sharing:

> *Huong: (interpreting Lien) Lien is willing to share with Centrelink... to get a benefit!*

> *Huong: (interpreting Lien) And insurance company, in-laws, and close friends only. But not to share with other irrelevant institutions. For example, tax office.*

Lien's remarks indicate how the user experience does not shed light on the governance of data: for example, Centrelink and the Tax Office being part of the Australian Government is not something made clear to users, nor is the degree to which private data brokers are now able to access a wide range of user data. This discussion raised the issue of how people's privacy and safety is maintained in the context of consumer-oriented digital platforms, where the transnational private governance of data industries contain few levers for regulation in the public or consumer interest (Butt et al., 2016).

Responses from participants in this study reflected the lack of clear information about how their data were likely to be used by private and public agencies. Their conception of a potential personal benefit for institutional data-sharing was not matched by an understanding of the mechanisms by which sharing actually takes place, suggesting a need for education in this area.

Data Sharing with Health professionals

In the next part of the workshop, participants were asked to consider which health professionals they would and would not feel comfortable sharing information with and why. Adeebah and Lien were unwilling for their oral health practitioner to have any information about their general health:

> *Adeebah: Yeah. I want to know for example, for, per year, how many times I want to clean our teeth, especially for adults, for us, and…. That one. How clean up, and how we do, how we look after…*

> *Lien (via interpreter) is not willing to share physical other disclose other health information not relevant to her oral health.*

The limited scope of information sharing for the oral health practitioner is significant given that oral health is an indicator of other health issues and social inequality and that the burden of oral disease is unevenly distributed to those who are less affluent (Sisson, 2007). This demarcation of professional trustworthiness with data and information was also evident for Nyaluok, who felt doctors should have greater access to her health information than nurses:

> *Nyaluok: Um, with doctors, sometimes, they prescribe and everything, so sometimes there are issues they'd want to know, when they prescribing you medications and all that, so. But nurses don't need to…*

However, Lien pointed out that they were part of a team who would work together and communicate information:

> *Huong: (interpreting Lien) She said information she gives to doctors and nurses and then nurse can report back to doctor.*

These perceptions of trustworthiness and sharing within a health care team have important ramifications for care planning, especially given the pressing need to facilitate communication, information sharing and collaboration between health-care teams and patients and carers (Lawn et al., 2015).

Data Sharing with Family members

Research on sharing health information has focused on a centralised depository of clinical information. However, there is limited research on the sharing of health information in social interpersonal relationships such as family and friends, despite family having a significant impact on how health is understood and engagement with health care systems (Crook et al., 2016). The theory of Communication Privacy Management (CPM) holds that individuals view information as something they own and wish to have control over, as disclosure can make them vulnerable (Petronio & Altman, 2002, p. 9). Participants were invited to consider which members of their families they would be happy to share different kinds of health information with, using the data boxes to model their information sharing.

Three women had very clear ideas about what information should be shared with parents, and that anything to do with contraception or sexuality was "private". Adeebah identified the boundaries of not sharing information related to sex as culturally specific:

> *Adeebah: Especially our culture, it doesn't… talking about like that!*

> *Nyaluok: Yeah. With that, it sometimes depends on cultural way. Some are limited talk about the things with parents, not because they don't want their parents to know, but because of the cultural thing you can't talk.*

A possible reason for concealing information about sexual activity is to avoid discomfort (Ebersole & Hernandez, 2016), but in the example given above, rather than personal discomfort it relates to a cultural taboo. Sharing pregnancy information was also viewed as complicated:

> *Nyaluok: Mm, if they agree and if there's a reason why they need to, yes, but I would…. complicated (laugh).*

> *Adeebah: Sometimes if you hide it until four months or five months, then it doesn't… that you're pregnant…*

> *Nyaluok: because if you get pregnant before marriage, you have to keep it a quiet secret for a very long time so it's something, very difficult for other people to say it.*

In this excerpt, sharing information about pregnancy may expose that sex had occurred outside of marriage and lead to questions about the "legitimacy" of pregnancy.

On the other hand, later in the group, Nyaluok said she would go to her mother for information:

Nyaluok: With pregnancy I always go to my mom. Especially with my first one. I don't know what are the signs of labour or whatever. I usually just contact my mom and 'what's this, I just googled it and it says this and that.' Google sometimes gives me scary stuff, but, so, yeah.

Nyaluok represents her mother as a trustworthy embodied source of information who can filter information and connect her to a more holistic, collective and historical normative account of pregnancy. This collective understanding of pregnancy resonated with a Vietnamese participant who was happy to share pregnancy information:

Huong: (interpreting Lien) and sometimes her parents gave her advice, including cultural advice, regarding what to do after pregnancy, during pregnancy, so she really appreciates her parents input. (unclear)

The value of this reciprocal exchange of information was echoed by a Chinese participant:

Maryanne: My parent is pretty open, so we have open discussions about health (unclear) pregnancy, anything about our health. (baby cries.) My father in law knows I'm smoking, so we're open about that and just health in general...

One participant was happy to share information with her sibling and vice versa:

Huong: (interpreting Lien) Lien says that she's got a brother, and they have their own family so they don't get in touch that often, but if she's asked, by her brother, about her health, she'll gladly let him know...So they call each other and give each other support and advice on this and that. NO problem. They can share.

However, another participant noted that it was more likely that her siblings would come to her as a source of information, rather than her sharing information with them, because of her birth order and being the eldest in the family:

Nyaluok: With me, because I'm the oldest, so it's more like they're coming to me more, most of the time, than me going to them and telling them my problems or my mental health and...If I'm involved in their care, yes, I would like to know, but if I'm not involved in their care, they will decide if they want to tell me or not. So I'm not gonna push them. But comparing my brothers, siblings and my parents, I'd rather go to my parents.

As the first born Nyaluok is the one her siblings turn to for advice, but she verbalises a preference for communicating with her parents rather than her siblings.

In-laws were seen as more complicated:

Nyaluok: Yeah, I would let them know my allergies, because, I might eat there sometimes. But pregnancy, my mother-in-law would be ok, no, not too much.

In contrast with sharing with her mother (which would be selective), Nyaluok pointed out she would want to share her health information and vice versa with her children:

Nyaluok: Yeah, if they are small, there are information they don't need to know. But if they are big, they are older, I'd love my children to know.

Huong: (interpreting Lien) Yes, she said she would let her children know about her health.. she wants to share and explain to them.

Methodological Findings: Design probes and qualitative methods

Based on this research we recommend the use of creative, design research interventions such as cultural probes and art-based methods as a way to elicit valuable information about non-dominant/diverse users of consumer health technologies. The cake (data) box design probe was effective for eliciting deeper conversations and unexpected insights and functioned as an alternative to survey-based methodologies which have suggested that people from CALD communities do not use consumer health technologies (Lupton & Pedersen, 2016).

As a design probe, the "cake box / data box" probe performed three main functions. Firstly, it allowed both participants and researchers to externalise their understanding of the themes being explored. Rather than relying on more extractive methods (like a survey or an interview), it allowed participants and researchers to collaboratively build, shape and check their understandings with each other through iterative shaping of materials. Working with a familiar object through craft allowed exploration of their ideal data box with various scenarios of use, while also allowing space for people to view the boxes as confronting or threatening.

Secondly, it took pressure off verbal and textual modes of communication and knowledge building by allowing participants and researchers to draw upon their understanding of the metaphors inherent in the materials and shapes recruited to use. This not only reduced anxiety within the CALD participant cohort by de-emphasising language comprehension as a pre-requisite to participation, but also allowed them to draw upon richer and more expressive knowledges; cellophane could be used to express opinions and uncertainties around *transparency*; holes within materials could be created, covered or changed to talk about *permissions*. Participants enacted agency over the cake box as a stand-in for a real data-garnering device in a way that wouldn't normally be possible due to the "black boxed" nature of consumer technology and informational platforms which don't readily afford visibility of their inner workings.

Thirdly, the boxes themselves, once created, acted as augmentations to other sets of expressions and knowledge practices. People were able to position the probes in relation to their bodies; proximity and distance became powerful metaphors themselves for all kinds of thematic explorations. When participants did choose to verbalise or otherwise perform their opinions and perspectives, they were able to point to and hold up the boxes as props or prompts to help their audience better understand and interpret their comments. Bringing sets of materials and metaphors to the table allowed richer, more embodied and expressive forms of understanding to be created.

Conclusion

Our pilot study revealed the value of creative methods for researching digital health literacy with groups who are typically viewed as being digital "have nots". Health literacy is often understood as a linear model of knowledge transfer, where information about health and about technology can be distributed from provider to patient. Indeed, many scales continue to be developed that attempt to systematise and standardise health literacy measures with a hope to find levers for larger scale interventions (Institute of Medicine et al., 2009). Our research suggests that for CALD communities in particular, health information flows are situated in complex, culturally-specific understandings of the individual's relationship to the system and their own family and community. Participants were aware of the ways that health information served the needs of multiple individuals and agencies, not just themselves, and they sought more control over where and with whom their data were being shared regarding institutions, families and communities in culturally specific ways.

It is therefore imperative that rather than research that seeks general solutions to digital health literacy in CALD communities, the relationship between actionable knowledge and social context are researched in terms relevant to culturally-specific groups. The new relationship between customisable information technologies and self-care suggests new opportunities for considering scale and reach in research, aligned with what Bobashev (2014) terms the "epidemiology of one". Based on this research, we believe that a reformulated, culturally responsive information system would allow expansion of the "epidemiology of one" to an epidemiology of community, understood through each person's holistic and specific web of relationships among family, caregivers, health professionals and technology providers.

The use of design probes in a speculative framework appears to hold promise for this kind of research into the relationship between complex concepts such as culture, gender, race, privacy and the lived experience of health literacy. Object-based discussion allows deeper and more nuanced conversations to unfold over time than more traditional interviewing, focus group or survey techniques. As the technologies underpinning digital health change as rapidly as the cultural makeup of our communities, we feel compelled as researchers to make our own methods more participatory, creative and responsive to meet this new conjuncture. We expect more of the methods associated with professional design practices to influence academic research among culturally and linguistically diverse communities in the future.

Acknowledgements

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