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Publications from this project

Findings from this project have been published in the outputs listed below. This report brings the main findings together from these publications and also provides additional material.

Lupton, D. (2018) ““I just want it to be done, done, done!” Food tracking apps, affects, and agential capacities’, *Multimodal Technologies and Interaction*, 2 (2). Available from <http://www.mdpi.com/2414-4088/2/2/29/htm>

Lupton, D. (forthcoming) ‘Caring dataveillance: women’s use of apps to monitor pregnancy and children’. In Green, L., Holloway, D., Haddon, L., Stevenson, K. and Leaver, T. (eds) *The Routledge Companion to Digital Media and Children*, London: Routledge.

Lupton, D. and Maslen, S. (2018) ‘The more-than-human sensorium: sensory engagements with digital self-tracking technologies’, *The Senses and Society*, 13(2): 190-202.

Maslen, S. and Lupton, D. (2018) ““You can explore it more online”: a qualitative study on Australian women’s use of online health and medical information’, *BMC Health Services Research*, 18(1). Available from <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3749-7>

Lupton, D. and Maslen, S. (2019) ‘How women use digital technologies for health: qualitative interview and focus group study’, *Journal of Medical Internet Research*, 21(1). Available from <https://www.jmir.org/2019/1/e11481/>

SUMMARY

A range of digital technologies are available to people to find, share and generate health-related information. Few studies have directed attention specifically to how women are using these technologies from the diverse array available to them. Even fewer have focused on Australian women's use of digital health technologies. The Australian Women and Digital Health Project aimed to investigate which types of digital technologies women used regularly for health-related purposes and which they found most helpful and useful. Qualitative methods – semi-structured interviews and focus groups that were recorded and transcribed for analysis – were employed to shed light on the situated complexities of the participants' enactments of digital health technologies. The project was comprised of two separate studies, including a total of 66 women (age range from 21 to 74 years). In study 1, 36 women living in the city of Canberra took part in face-to-face interviews and focus groups, while study 2 involved telephone interviews with 30 women from other areas of Australia. A feminist new materialism theoretical approach was used to analyse the interview and focus group transcripts.

The findings demonstrate the nuanced and complex ways in which the participants were engaging with and contributing to online sources of information and using these sources together with face-to-face encounters with doctors and other healthcare professionals and friends and family members. They highlight the lay forms of expertise that the women had developed in finding, assessing and creating health knowledges. The findings also emphasise the key role that many women play in providing advice and health care for family members not only as digitally engaged patients but also as digitally engaged carers. Many women reported using internet resources to provide health advice and support to family members and friends as well as receiving advice as part of their existing caring and social relationships.

All of the participants said that they accessed both online sources and face-to-face sources of health information regularly. All referred to visiting doctors and other healthcare professionals, and the majority noted that in-person interactions with family and friends were also a key source of health information for them. For the most part, traditional media forms, such as books, were not highly used. However, printed pamphlets remained influential sources for about half of the participants. In terms of digital technology adoption, using a search engine to search for health information online was a universal practice among the participants. Health and fitness apps were used by over half of the participants. Calorie-tracking apps such as MyFitnessPal and Weight Watchers and physical activity apps for monitoring heart rate, calories burnt and steps taken or providing workout or yoga programs and routines were by far the most often mentioned. Social media were used less frequently (a third of participants), with Facebook groups most often mentioned as social media sources of information about health. One in five participants were currently using a wearable device for health-related purposes, with Fitbit fitness trackers and Apple Watches the most popular. Small numbers of women said that they used digital self-care devices to manage a chronic health condition or exercise games like Wii Fit, while none reported using online physical fitness platforms like Strava. Many participants demonstrated a lack of awareness of and interest in the Australian government's electronic patient record, My Health Record. Only one-third had signed up, suggesting that attempts by the government to publicise and promote the system have not been effective.

For women with chronic health conditions and those caring for infants and young children, in particular, online forums and social media groups were often used as a form of lay creation and sharing of knowledge. The key benefits of online peer sources were the opportunity to share experiences as well as ask advice and find support from other people experiencing similar illnesses or life events. The participants particularly valued being able to access a more personal form of information that provided insights from others' experiences.

While they were very active seekers of online health and medical information, the majority of participants expressed caution about its accuracy and validity, and, in some cases, expressed difficulties in knowing how to assess this information. The women described various strategies to determine whether or not the information they found could be trusted, including looking for government-related websites (such as those run by Departments of Health) and preferring Australian sources over non-Australian (because they were considered more relevant). Most women acknowledged that online sources supplemented rather than replacing the expertise and advice of medical practitioners. This was particularly the case for general practitioners (GPs) who the women had been seeing for years and knew their medical history well.

The women who were using health and fitness self-tracking apps and wearable devices appreciated the better knowledge of their bodies that their practices gave them. They reported struggling with weight loss or attempting to increase their fitness levels. Being able to use an app or wearable device to closely monitor their bodies helped them to exert control over their bodies. Pregnancy and parenting apps were also highly used among women in those life stages to help them cope with the demands and challenges of caring for and monitoring their children. However, while these apps and devices were useful and helpful for many women, the participants gave several examples detailing the deficiencies of these technologies. They had encountered problems in successfully using the apps and wearable devices that centred on such issues as poor design, lack of accuracy or failure of the technologies to produce promised or expected outcomes. Even those who had used self-tracking apps and wearables for some time could become bored, or disliked the constant notifications they received.

For the most part, the participants expressed a lack of interest or concern about the security of their personal health data. They explained that this was due to several factors: a belief that their data were well-protected or that no-one would be interested in their health details, resignation to the fact that there was already a lot of their health information online, not having thought much about the issue, not realising that their information could be accessed and used by third parties or simply investing their trust in the companies that they used. It was difficult for most participants to identify what might happen to their personal information traces when they went online or used apps. Most of the women had not yet been directly affected by third-party use of their health data and therefore were not placed in a position where they needed to consider privacy and security issues.

The final question asked the participants what new digital health technology they would like to see invented to suit their needs. The participants envisaged new technologies that would be even more convenient and personalised than the current range available to them. Many of their responses referred to apps or devices that would work better to assist them with weight-loss or physical fitness efforts. Another common idea put forward was an imagined device that would combine many of the features they find useful. Some participants imagined an app that could combine the search features of Google with the functionality of an app to help them find information about symptoms and other health issues. Alternatively, women suggested an app or platform that would bring together health data from a number of different sources so that they could all be in one place and could then be readily shared with healthcare providers. Some women said that they wanted more direct contact with medical expertise using online technologies.

INTRODUCTION

Over the past three decades, a range of digital technologies for sharing and generating health and medical information has emerged. This began in the mid-1990s, following the invention of the internet and the World Wide Web, with the establishment of information websites, email-enabled listservs, blogs and online discussion forums for lay people to access details about health and medicine and share their own experiences. More recently, mobile devices constantly connected via Wi Fi, social media platforms, mobile applications ('apps') and wearable self-tracking devices have become available to enable people to seek online information at any time and generate and share their own health data and experiences of healthcare and illness. Recent healthcare policy emphasises the importance of active patient engagement with medical expertise, the incorporation of lay expertise into healthcare delivery and patient responsibility for the understanding and managing their chronic health conditions (Taylor and Bury 2007; Rogers et al. 2009; Hinder and Greenhalgh 2012; Greenhalgh et al. 2013). People are now often expected to be 'digitally engaged patients' (Lupton 2013a), actively using digital technologies to seek out information about health and medical issues and manage and promote their health.

Despite this move towards encouraging digital patient engagement, healthcare providers are not always receptive to patients who present in consultations armed with information they have accessed online or generated about themselves using self-tracking devices (Rupert et al. 2014; Smailhodzic et al. 2016; Benetoli et al. 2018). Concerns about patients finding or sharing inaccurate information online (Davis 2017), developing 'cyberchondria' (extreme unfounded anxiety about illness) (Doherty-Torstrick et al. 2016) and erosion in the public's trust in medical expertise (Schulz and Nakamoto 2013; Davis 2017) have been expressed in the medical literature. Indeed, one commentator has contended that patients' use of the internet to access health and medical information is a 'patient autonomy problem' that leads to patients investing more trust in the internet than in their doctors' expertise (Davis 2017). These claims suggest concern about the contemporary status of medical authority in the context of the ever-expanding domain of health and medical information offered to lay people (Lupton 2017a).

The gendered dimensions of the design and use of digital health technologies have received little attention thus far. Most of these technologies are designed for the universal user: an individual typically assumed to be white, male, well-educated and well-off. This can mean that devices do not fit well on female bodies, or that menstrual tracking options are not initially included in smartwatch design (as was the case of the first Apple Watch, for example). Some female bodily experiences such as menopause or problems with pelvic floor strength tend to be ignored (Almeida et al. 2016; Epstein et al. 2017), while others, such as fertility, pregnancy and early motherhood, receive far more attention.

This report presents the findings from my Australian Women and Digital Health Project. This project is innovative in several ways. First, it included Australian women across a range of ages, education levels and geographic locations. Second, rather than focusing on specific digital health technologies, it covered the full range currently available to Australian women. Third, it investigated the contextual details of the participants' lived experiences of digital health by using qualitative research methods that invited them to discuss these experiences in detail. Fourth, the project included direct questions about whether the participants had thought much or were concerned about how well their health and medical data were protected or used by third parties, an issue that has rarely been addressed in previous studies of women's use of digital health technologies. Fifth, the women were asked to imagine what digital technologies they would like to see designed to promote their health, thus incorporating a future-oriented perspective into the research. And finally, an innovative feminist new materialism theoretical approach was used in the analysis of the interviews and focus group discussions.

Theoretical perspective: feminist new materialism

Feminist new materialism is one branch of new materialisms scholarship. A range of eclectic perspectives are included under the rubric of new materialisms. They share a critique of and focus on interrogating the nature of the 'human', including acknowledgement of the actors (including those normatively considered to be 'nonhuman') that come together to configure the 'human' (Braidotti 2018). Feminist new materialism theory, as advocated by scholars such as Jane Bennett (Bennett 2001; 2010), Karen Barad (Barad 2003; 2014), Donna Haraway (Haraway 2016; Franklin and Haraway 2017) and Rosi Braidotti (Braidotti 2016; 2018), recognises and emphasises the relational engagements of people with technologies as well as with other people, and the dynamic nature of these engagements. From the feminist new materialism perspective, human subjects are not just knowing: they are also sensing, embodied, affective

assemblages of matter, thought and language (Braidotti 2018). The relational approach advocated by these scholars sees agency as distributed between humans and nonhumans and as always emergent rather than possessed by any sole actors. Matter (otherwise understood as things, objects, bodies, spaces and places), Barad argues, is ‘an active participant in the world’s becoming’ (Barad 2003: 802). Together, humans and nonhumans generate affective forces and agential capacities that are constantly made and reconfigured, responding to movements, encounters and actions (Barad 2003; Bennett 2009; Haraway 2016).

When addressing people’s use of digital technologies, a feminist new materialism approach focuses attention on the ways in which humans come together with digital technologies to generate agential capacities, acknowledging the role of the affordances of both human bodies and technologies, the relational connections between the various actors involved and the affective forces that are vital to the ways in which capacities can be opened up or closed off. The affordances of fleshly human bodies include their sensory perceptions, emotional responsiveness, embodied expertise, memory and the ability to learn and to move in certain ways. The affordances of nonhuman objects such as digital technologies relate to the design features of these technologies and what they potentially allow people to do with them. Relational connections include the ways in which humans interact with and respond to other humans, as well as with nonhumans, and how these relationships contribute to or generate bonds and affects. The concept of affective forces views affects as impelling action or other responses. Affects are understood as distributed forces that are shared between members of human-nonhuman assemblages, working to impel action and responses.

Complex engagements of actors in these assemblages generate agential forces and relational connections that are always contingent and dynamic, depending on the actors that enter or leave assemblages and on time, space and place. Together, these elements contribute to the agential capacities of human-nonhuman assemblages that gather when people are trying to make sense of their bodies and health and illness states and promote their health and wellbeing. This approach is able to site digital technologies and their affordances into the more-than-human worlds in which people come to understand and perform health and illness.

Previous research

The vast array of resources about health and medical issues that can be found on the internet or presented in health and medical app is a boon for lay people. Previous research conducted in countries in the Global North has demonstrated the benefits many lay people, both men and women, can gain from engaging with online sources of health and medical information such as websites and patient discussion groups (for overviews of this research, see Kivits 2013; Lupton 2016b; 2017a). Several studies have shown that that women are higher users of online health and medical information than men (Bidmon and Terlutter 2015; Montagni et al. 2018). Information websites, online discussion groups and patient-authored blogs about health and medical topics have helped diverse groups of women, including those with metastatic breast cancer (Vilhauer 2009) or seeking information about breast cancer (Unruh et al. 2004), women searching for information and support in relation to endometriosis (Shoebotham and Coulson 2016) and women with multiple sclerosis (Sosnowy 2014).

However, some groups of women are less likely to see health information online than others. Factors such as ethnicity/race and education level can influence women’s internet use for health information (Narasimhulu et al. 2016; Walker et al. 2017). For example, racial and ethnic differences were investigated in a survey of young (18 to 24-year-old) American women. The study found that most of the white and black participants used the internet, while fewer Hispanic respondents did so. Of those young women who were internet users, there was little difference between the proportion of those who sought health information, although white and Hispanic women did so more than black women (Laz and Berenson 2013). Other research on middle-aged and older women with chronic health conditions in the USA found that the older women were much less likely to seek health information online, preferring face-to-face engagements with healthcare providers or family and friends to seek and share information (Pettus et al. 2016).

The bulk of research related to women’s use of online health sources has focused on digital media for pregnancy and parenting (Lupton et al. 2016). Numerous studies over the past five years demonstrate that in countries as diverse as the UK (Gibson and Hanson 2013; Orton-Johnson 2017; Prescott and Mackie 2017; Pedersen and Lupton 2018), Ireland (Mullaney et al. 2015; O’Higgins et al. 2015), USA (Walker et al. 2017), Italy (Bert et al. 2013) and China (Gao et al. 2013), blogs, information websites and discussion forums remain popular among women. Research has demonstrated how helpful women can find these online media, including those experiencing distress due to

pregnancy loss (Betts et al. 2014) or problems in conceiving and infertility (Costa Figueiredo et al. 2017) and women discussing experiences of childbirth (Das 2017) or emotional challenges in dealing with motherhood (Pedersen and Lupton 2018). This research has demonstrated how much women appreciate being able to easily find both medical expert advice and support from other women, who are often located across the globe, experiencing similar health and medical conditions and to share information with each other. Some groups of women, however, have been found to use online sources for pregnancy and parenting less often, including low-income women (Song et al. 2013; Guendelman et al. 2017; Zimmerman 2018), due to factors such as limited access to digital technologies, lower education levels and a preference for face-to-face medical advice.

Recent research has also shown that the newer technologies of social media platforms and smartphone apps for pregnancy and parenting are commonly used by women in countries as diverse as Germany (Wallwiener et al. 2016; Goetz et al. 2017), Korea (Lee and Moon 2016), Italy (Scaioli et al. 2015), Turkey (Şat and Sozбір 2018), Canada (Price et al. 2018) and the USA (Morris ; Kraschnewski et al. 2014; Ammari et al. 2015; Asiodu et al. 2015; Holtz et al. 2015; Kumar and Schoenebeck 2015; Tomfohrde and Reinke 2016; Andalibi and Forte 2018; Harpel 2018; Skelton et al. 2018). In terms of social media use, most of this research has focused on Facebook, as the most commonly-used social media platform in many countries, but breastfeeding selfies (Boon and Pentney 2015) and discussions of this practice on Instagram (Locatelli 2017) have also been explored. Some studies have also investigated British women's use of ovulation monitoring devices (Wilkinson et al. 2015) and American and Scottish women's period tracking apps (Epstein et al. 2017; Gambier-Ross et al. 2018), demonstrating that women appreciate being able to monitoring their cycles for better predictability, understanding their bodies or for avoiding or planning pregnancy. Here again, however, studies have revealed that some social groups are less likely to make use of digital health technologies. German researchers found that younger pregnant women and those in their first pregnancy were more likely to use health apps (Wallwiener et al. 2016), while Italian researchers also noted differences between groups of pregnant women based in their age and education level, as well as their geographical origin (Scaioli et al. 2015).

Beyond the specific domains of fertility, pregnancy and early parenting, thus far little research has focused on women's use of apps, wearable devices and social media for health-related purposes. It has been demonstrated that women who engage in self-starvation and disordered eating practices use social media platforms, including Instagram, Tumblr and Twitter, to find support from like-minded others (De Choudhury 2015; Cobb 2017; Eikey and Booth 2017; Ging and Garvey 2017; LaMarre and Rice 2017) and employ weight-loss apps as part of their calorie-consumption monitoring and restriction practices (Eikey and Reddy 2017; Eikey 2018). Women interested in advocating or supporting body positivism and fat activism have also facilitated communities on social media (Pausé 2015; Marcus 2016).

Some studies involving both women and men have identified gendered differences in how people use health and fitness apps. For example, a French study (Régnier and Chauvel 2018) involving interviews with people aged from 20 years to over 50 who had tried using self-tracking diet and fitness apps noted that women were more likely to use diet apps, while more men used fitness apps. Older women were more resistant to using either type of app and more likely to use them for only a short time. Some survey-based research has shown that women tend to use health apps more than men, including studies in Hong Kong (Xie et al. 2018) and the USA (Carroll et al. 2017). However, a survey of older Germans (aged over 60) found that men were higher users of health apps than women (Rasche et al. 2018) and another recent German survey of adults found little gender difference in health app use (Ernsting et al. 2017). A Nielsen market research report on Americans' use of wearable devices for self-tracking found that women are more likely than men to use diet and calorie-counting apps on their devices (Nielsen 2014). One qualitative study has investigated how adolescent girls interested in sport use fitness tracking apps, finding a degree of ambivalence in the participants, particularly in relation to the competitive elements of the apps (Depper and Howe 2017).

Only a small number of studies published thus far have addressed Australian women's use of digital health technologies. Research has demonstrated that Australians in general are high users of mobile devices and social media. A 2018 representative consumer survey of adult Australians (Yellow 2018) found that 87% of respondents owned a smartphone and just over one-fifth (21%) owned a wearable device such as a smartwatch or fitness band. Sixty percent accessed the internet over five times a day. Facebook was by far the most popular social media platform among social media users (91%), followed by YouTube (53%), Instagram (39%), Snapchat (23%), LinkedIn (22%), Twitter (19%) and Google+ (13%). In terms of gender differences, Australian women were slightly more likely to own a smartphone (89% compared with 86% of men), tablet device (63% compared with 56%) and wearable device (22% compared to 19% of men). While women were only slightly more likely to access the internet five or more times a day

(62% compared with 58% of men), they were far more frequent users of social media than men. Forty-one percent of women accessed social media five or more times a day, while only 26% of men did so. Female respondents who used social media were more likely than men to be on Facebook (94% compared to 88%), Instagram (44% compared to 34%), Snapchat (28% compared to 17%) and Pinterest (31% compared with 11%), but less likely to use Twitter, LinkedIn and YouTube.

As with other geographical locations, most Australian-based research on women's use of digital technologies for health-related purposes focuses on pregnancy and parenting. These studies have demonstrated that Australian women experiencing these life stages are keen users of social media and apps to find information, communicate and connect with other mothers and track their pregnancy and children's development (Hearn et al. 2013; Rodger et al. 2013; Johnson 2014; 2015; Lupton 2016c; Chalklen and Anderson 2017; Lupton 2017b; Archer and Kao 2018). Research investigating Australian women's use of digital health in life stages other than pregnancy and early parenting include a large survey of Australian young women (aged 18 to 24 years). Findings revealed that only 43% had used the internet to search for health information. Those women experiencing stigmatised conditions or symptoms (such as mental health problems) were more likely to have searched online than other participants (Rowlands et al. 2015). Another study of young Australian women diagnosed with a sexually transmissible infection showed that they found both face-to-face and online sources valuable for advice and support (East et al. 2015).

METHODS

The Australian Women and Digital Health Project was designed to investigate the following research questions: What digital technologies do women use regularly for health-related purposes, both for themselves and for any others (family members or friends)? Which do they find most and least helpful and useful? What kinds of digital health technologies would they like to see developed in the future? Qualitative methods – semi-structured interviews and focus groups – were employed to shed light on the situated complexities of the participants' encounters with digital health technologies.

The project was comprised of two separate studies. A total of 66 women participants across the two studies were involved in either interviews or focus groups about their use of digital health technologies, taking place from November 2016 to August 2017. These interviews and discussions were audio-taped and transcribed for analysis. Ethics approval to conduct this research was granted by the University of Canberra human ethics research committee. All participants were provided with project information and gave their consent to participate. They were all given pseudonyms to protect their anonymity.

The same semi-structured interview schedule was used with all participants. These questions began with a broad contextual enquiry into how participants accessed health and medical information (including digital and non-digital sources) and which of these sources they found most helpful or useful. They were then asked specifically about which digital technologies they currently used for their own purposes or on behalf of family members for health or medical reasons. They were again asked to explain which were most helpful or useful and which were not, and provide details on why, and also to elaborate on how they thought these technologies could be improved to better suit their needs. The participants were then asked if they had signed up to the Australian government's electronic health record system (My Health Record) and to explain their reasons for doing so or not doing so. Then followed a question about their personal health data, and whether they had ever thought about where the personal information that these technologies collect about them or their family members go and who uses it, and whether they were concerned about others accessing or using this information. The penultimate question asked participants to consider if they were designing the ideal digital health technology for their everyday needs, what it would be and what it would do. Finally, they were provided with the opportunity to make any further comments about digital health technologies and how they used them. These questions provided the basis of the interviews and group discussions, but interviewers also probed participants for further comments and explanations of their responses.

Participant details

Study 1 involved three sets of women living in Canberra, totalling 36 participants. The first set included a total of 11 women who attended an initial community forum which was advertised among women's community health groups by the Women's Centre for Health Matters, a community-based not-for-profit organisation that works in Canberra and surrounding regions to improve women's health. The participants who attended the forum were divided into two focus groups, one of which was led by myself and the other by a staff member from the Women's Centre for Health Matters. Their ages ranged from 28 to 65 years. The forum was used to identify key issues and further develop questions for further interviews and focus groups.

Following this forum, another 12 participants (aged from 21 to 63 years) were recruited to take part in individual face-to-face interviews. Three further focus groups with a total of 13 women were also conducted. One focus group consisted of six women with young children (aged from 25 to 33 years), the second included four women with young children who were part of a support group for mothers living with mental health conditions (aged from 25 to 30 years) and the third focus group included three women aged in their mid-to-late 50s. Of the total of 36 women involved across these Canberra participant groups, 28 identified their ancestry as Anglo-Celtic and eight as Asian. Twenty-two participants reported university-level education, while 14 had high school or technical qualifications. These interviews and focus groups were conducted by two research assistants employed on the project. The participants were recruited using Women's Centre for Health Matter's networks, personal contacts, advertising on relevant Facebook pages (such as those for mothers, people with disabilities and women's fitness and sporting groups in Canberra) and posters in public places around the city. They took place in a range of locations, including places where the focus group participants usually met, homes and cafes.

Study 2 involved telephone interviews with 30 women living in various locations around Australia. A market research company was commissioned to recruit the participants and conduct the interviews. Participant information and consent were provided online before the interviews were conducted. This group of participants were recruited using sub-quotas based on age, to ensure a good spread of ages: ten aged 18 to 40 years, ten aged 41 to 60 years, ten aged 61 and over. These participants ranged in age from 22 to 74. Two-thirds lived in major cities and one third lived in rural or remote Australia. Twenty participants lived in the state of New South Wales, four in Queensland, five in Victoria and one in Western Australia. Twenty-five participants described themselves as having Anglo-Celtic ancestry, one as western European, two as southern European, two as Asian and one as middle Eastern. Of this group, 14 reported university qualifications, and the remaining 16 participants had high school or technical qualifications.

Table 1 summarises the participant details.

STUDY 1 (CANBERRA)	Community forum (2 groups): 11 participants, age range 28–65 Face-to-face interviews: 12 participants, age range 21–63 Focus groups (3 groups): 13 participants, age range 25–58
STUDY 2 (AUSTRALIA-WIDE)	Telephone interviews: 30 participants, age range 22–74

Table 1: *Participant details*

Analysis

All the group discussions were audio-taped and transcribed by a professional transcription company. I analysed the transcripts using a method of inductive thematic analysis (Ezzy 2013) informed by feminist new materialism. This involved identifying recurring themes within and across each group discussion by reading and re-reading the transcripts, locating the places where the participants talked about the digital information that they accessed from online media and considering the following dimensions drawn from feminist new materialism theory (outlined earlier): the affordances of the human bodies and technologies involved; relational connections between the humans and technologies that were developed; the affective forces that impelled the women's actions and responses; and the agential capacities that were generated when these dimensions came together.

FINDINGS

Overview

The interview and focus group discussions opened with a contextualising question asking participants what sources they currently used to access health information. They were specifically asked about every source listed in Table 2, which provides an overview of their responses, and also had the opportunity to list other sources.

As shown in **Table 2**, all of the participants said that they accessed both online sources and face-to-face sources of health information regularly. All referred to visiting doctors and other healthcare professionals, and the majority noted that in-person interactions with family and friends were also a key source of health information for them. For the most part, traditional media forms, such as books, were not highly used. However, printed pamphlets did remain influential sources for about half of the participants, particularly as they were available when they were waiting at doctors' surgeries for appointments. Other sources of health information were nominated by small numbers of participants (categorised together as 'Other' in the table). These included a medical phone service, videos, podcasts, information sheet about a medication provided by pharmacist, asking a pharmacist for information, emailed newsletters from groups, magazines, newspapers, television advertisements and television health programs/documentaries.

SOURCE	%
doctors/other healthcare providers	100
online sources	100
friends and family	85
pamphlets	48
books	18
other	20

Table 2: Health information sources currently used, % (n=66)

The next question asked participants to specify which digital health technologies they currently used. Again, they were specifically asked to respond to each technology listed in **Table 3**, which gives an overview of their responses.

TECHNOLOGY USED	%
search engines	100
websites	90
apps	57
social media	33
online discussion forums	27
wearable device	20
exercise games	13
self-care devices for chronic illness	13
physical activity platforms	0
other	14

Table 3: Digital technologies currently used for health, % (n=66)

As **Table 3** demonstrates, using a search engine to search for health information online was a universal practice among the participants. Google Search was the only search engine mentioned by the participants: they typically referred to 'googling' or consulting 'Dr Google' when describing this practice. Health and fitness apps were used by over half of the participants. Social media were used less frequently (a third of participants), with Facebook groups most often mentioned as social media sources of information about health. One in five participants were currently using a wearable device for health-related purposes, with Fitbit fitness trackers and Apple Watches the most popular. Small numbers of women said that they used digital self-care devices to manage a chronic health condition or exercise games like Wii Fit, while none reported using online physical fitness platforms like Strava. When asked if they used any other digital technology for health-related purposes that had not been listed, two said they played mind-fitness games online, and another four women referred to using email to send articles to family members or friends about health issues or being part of email groups set up for health-related topics, while three mentioned watching YouTube videos about health issues.

Search engines and information websites

Using search engines – and in particular, Google Search – to find health and medical information was a universal practice for all the women, regardless of their age, geographical location or level of educational attainment. It was common for women to say that they go online very regularly: several times a week, in some cases. The definition of 'health'-related information was quite broad in women's accounts. It was interpreted by some women to mean baby care, fitness advice, weight loss, diets or healthy eating or cooking sites, discussion groups or social media groups, as well as sites that offered information about symptoms or medical conditions and treatments.

The participants noted that they valued online sources highly because they were accessible at any time, free to use, and could be consulted at length, without time constraints.

Well it's in the palm of your hand. You can access it anywhere 24/7. Even last night I had to take my daughter to her band practice which doesn't finish until about 10 o'clock and I'm sitting in the car for two hours waiting for her. So that's when I google and surf the net and read all my stuff. It's portable, you can take it anywhere and they don't shut off at a certain time. And so if I take the kids somewhere and I'm waiting for them, I do what everyone else does and jump on my phone and look. (Julie, aged 51)

Using Google Search is like opening an encyclopaedia and you get all the information you need. And it's more specific so you can use your key words to get exactly what you're after. Well it's just so quickly and easily accessible to get an answer, I guess. It's so convenient. (Amelia, aged 24)

The sheer range of health and medical information online was a key affordance that was valued by most participants. As one woman explained, googling for information allowed her to find health information for herself and her children across a diverse range of topics:

You can get results for what you're searching for whether it be something related to me specifically like my own workout or food or my own wellbeing like probiotics to take and that kind of thing, or it's something related to my daughter like baby food or that kind of thing. Or it's just something for my older child you know websites specific to her disability or googling about medications or conditions, because I pretty much do all the health sort of stuff for the whole family. You can use the internet whenever you like, you don't have to wait for a doctor's appointment. (Hannah, aged 34)

Participants also valued the currency of online information.

It's easier to see when the information was updated. Books – you can get a book where you might think it's a really new one and then realise it's five years old and it's out of date. So just the information is more readily available, it's more current. (Susan, aged 56)

More specifically, online sources could provide direct access to the latest medical research (for example, open access online medical articles) and medical information (websites like PubMed, WebMD and apps for self-diagnosis) in ways that were not available in the past: 'I go to PubMed. Yes, that's the one all the universities use. It has all the research. It's got a wider range of research and it's likely to be up to date' (Robyn, aged 64).

Visits to medical practitioners were far less frequent than searches online for health and medical information. The women commented that consulting a doctor was much more time-consuming: it involved taking additional time to make an appointment that could fit into people's schedules and to attend the appointment. People who had poor access to the type of health services they needed also appreciated online resources. Medical services are not always available when they are required, either because it is a weekend or because people live in a location where services are stretched. In these cases, online sources offer an alternative. One example is Paula, aged 36, who lives with bipolar disorder. She has limited access to mental health services in her small town and must travel for several hours to see a specialist:

I go online because I can access that easily and it doesn't cost me anything, and I don't have to make an appointment time to access it, compared to having to set aside a day for travel and everything, to go out of town for what might not be helpful in the end, anyway. It can be up to a week before people can get in to see doctors here, so if you want information, like, then and there, or sooner than a week, it's easier to go online and try and source it yourself.

For some women, the expense of a doctor's consultation was also a factor that deterred them from seeing doctors too often or too readily, if their doctor did not bulk-bill and there were out-of-pocket fees to pay for.

It's definitely more accessible, trying to get a doctor's appointment obviously can be time consuming and you may not get the appointment that you need. It could be something very, very simple that you can deal with yourself. The accessibility is paramount really. The fact that you've got access to so many different ways of looking at your health, of helping I think its invaluable. (Sandra, aged 55)

Women were not only searching for health and medical information on their behalf. Many described how they incorporated going online to seek this kind of material as part of their family caring roles. They discussed looking for details on behalf of their children (including adult children), grandchildren, their partner, or elderly parents.

A little while ago, my son – he's had enuresis, bed-wetting, for a very long time – so I'm always looking at ways to help him with that. And even just a couple of months ago, my daughter, had a serious bout of chickenpox, she was off school for six weeks. So you always google things, remedies, what to look for, how long does it last, what's the infection period. So, even though we went to the doctor to get the prescription for the antibiotics, I still like to google the information. (Julie, aged 51)

I've got a son who has Asperger's syndrome, which is a form of autism, and quite often I'll access information to see if there's anything new coming out. My husband has type 2 diabetes and a heart condition so quite often I'll do research to see if there's anything new coming out about that. (Susan, aged 56)

My mother-in-law had shingles, and so straight away I'd go to Google and try to find out what the symptoms are, you know, how to cure it, what's the best way to treat it, that sort of thing. (Sandra, aged 55)

It was evident from some women's accounts that they viewed the practitioner consultation as largely confirming their self-diagnosis or their diagnosis of a family member after accessing relevant information online. This confirmation is critical because the practitioner has diagnostic expertise, as well as the authority to prescribe medication or refer patients to specialists for further treatment.

I tend to go to a medical practitioner if I feel it's serious enough. If not, I do the Dr Google, I guess, and have a look online. But I don't rush off to the doctor with any little thing, I make sure I've got symptoms that warrant something like that Recently when I had a prolapse. I looked up symptoms of prolapse to confirm my suspicions and then I went to a medical practitioner. (Sharon, aged 59)

[Searching online] sort of assists me in planning what I should do – whether it's something I should go to the doctor about or whether it's something that I can handle myself. I know you shouldn't, but it's what I do use it for. A diagnostic assistant. (Margaret, aged 73)

As some women's responses demonstrate, people are aware that the medical profession often frowns on patients using 'Dr Google' (as Margaret says, 'I know you shouldn't'), but they are also conscious of the importance of not seeking medical attention if it is unwarranted. As several participants noted, it depends on the seriousness of the health condition to what extent they sought further medical advice. Conducting a search online is a way of determining whether their or a family member's symptoms are 'serious enough', as Sharon notes, to make the effort to take further steps involving consulting a doctor.

Amelia, aged 24, has two young children, and says she visits the doctor almost monthly on their behalf or her own. Before deciding whether to make an appointment, she conducts some research online. This means that in some cases, she can avoid having to go through the logistics of taking herself and her children to consult a doctor.

Well I guess if there's just a few symptoms that they've got I might just look it up [online] instead of going to the doctor. If they're mild symptoms, whereas if it's something I'm more concerned about I'll go to the GP for the assurance ... Well it's just so quickly and easily accessible to get an answer, I guess. It's so convenient. You might not want to go out because you've got the kids so it gives you that time to reassure yourself before going to seek medical advice.

Women with chronic health conditions were among the most active in their seeking of online health information for self-diagnosis. Louisa, aged 30, lives with several chronic pain conditions, to the point that she is too unwell to work, although she studies part-time at university. She said:

I self-diagnose a lot because quite honestly, I know my body better than they do. I have two doctors who basically go, "Well I think it could be this, do you want to go home and google it and tell me what you think?" They trust me with Google enough to do that. Just the other day, last Thursday I think, my doctor said to me, "I want you to try this new medication, but you've got to go home and read about it first and see if you decide if it's what you want to try or not."

Participants often made reference to the ways in which an initial web search could alleviate concerns about a health problem they might have for themselves or family members.

Health websites can ease worries. You know, sometimes you'll look at something and you think "Oh I wonder about that." And then you find that it's something quite common or nothing to be concerned about, so it eases worries, because it's probably written in a more layperson's language – more understandable. (Margaret, aged 73)

In some cases, the participants had been able to find a diagnosis using online information and then track down an effective treatment for a condition. Diane, aged 56, described how she had done this on behalf of her grandson:

We don't want to race to the doctors, so we might have a look at it and I'll look up to see what natural therapies would be useful for that ailment. I will either tell my daughter or email her what I've found and she can do something about it or yes, we can do that together. For example, we had what we thought was an eye infection and we found out that a certain natural therapy called colloidal silver. And yeah, she had that and we were able to put colloidal silver in his eye and it cleared it up.

Houda, aged 45, gave an example of how she had managed to find a treatment for a recurring health condition for which she has been unable to find effective medical advice:

A few years ago, I was constantly getting boils, and my doctor was putting me on antibiotics. And I thought, "No, there's got to be more information", so I went through Google and watched some YouTube videos and it turned out it was all related to diet. So I went on an auto-immune response diet and I don't get boils anymore! I worked out what the culprit was and it was the food that I was eating. My doctor never once said it had anything to do with diet, just constantly putting me on antibiotics. I was watching people who have gone through the same thing

and what they did and it was really helpful. If I never found that, I'd be still stuck on the same thing, I'd just be on antibiotics all the time.

Several women recounted their experiences of using the internet to prepare for a medical consultation, so that they would be able to use the medical encounter most effectively. This might involve using the information they have found online to behave assertively with healthcare providers. As Marilyn, aged 67, commented:

Anything that shows up for me, I normally google it and look through it, see if I can get any clues to what it is. And then when I go and see the doctor about it, I demand to have the sort of care that I'm supposed to get instead of being patted on the head and sent away.

Women also used their online research to start an initial conversation with their doctors, relying on the medical expertise of their doctors to affirm or evaluate what the women had found online. Katrina, aged 38, lives with ulcerative colitis, a chronic digestive disorder, and consults regularly with her general practitioner. She noted that:

I find that if I do the web stuff before I go to the GP, I feel I'm a bit more prepared to hear what they're probably going to tell me and get reassurance from them. So – I mean, I kind of think I'm a fairly health literate person. So in my case I'm quite happy to look up things on the internet and be like well, that's from a relatively good source, that's from a dodgy source or whatever. But at the end of the day I don't have a degree – a medical degree anyway. So I would like to go and see my doctor or my specialist just to make sure that what I'm thinking is actually the same thing.

The participants also described searching for further information once a diagnosis had been made by a medical professional. Online sources were used to fill gaps in information or explanations of illnesses that participants or their family members received from medical practitioners.

My mum has a lot of health issues so she's always got questions about things. I use Google to do some further research on things doctors might have told her and things that are a bit more technical. Well she had bulging discs in her back so they were telling her to have surgery and she wasn't sure so I gave her more information on what was involved in the surgery, all those kinds of things. The doctors aren't always good at explaining things in layman's terms. (Amelia, aged 24)

For instance, if you go to the doctor and they tell you you've got high blood pressure you would maybe just have a look to get more information about something that the doctor has diagnosed you with. Well with the doctor you're only there for a limited amount of time so they probably can't tell you everything single little thing there is to do with it. (Jodie, aged 45)

Other women described going online to seek out further information if they or a family member had received medical attention but their condition was not diagnosed or adequately treated.

One of my sons has a severe depressive illness and has been quite resistant to treatment. So the medications he's on aren't necessarily meeting his needs or addressing the problem correctly. So I've been trying to get as much information about taking alternative treatments that he might be able to try or finding out resources for him. ... Well I would either send him a link to have a look at or show him on my tablet or on my phone or whatever. Just so that he's aware of it and he can look at it. (Lynne, aged 55)

Discussion forums and social media

Many women also referred to the value of accessing peer communities such as patient support forums and Facebook groups established to share information about health and medical topics or specific conditions. The key benefits of these sources were the opportunity to share experiences as well as ask advice and find support from other people experiencing similar illnesses or life events. They particularly valued being able to access a more personal form of information that provided insights from others' experiences.

Just the really interesting things people put on there and real-life experiences and what they've gone through. They give you information, like links to go through, you can either take it or leave it. It's up to you what you get out of it. (Houda, aged 45)

Some women said that they valued the privacy that online forums and social media afforded them, meaning that they could see what other people were saying about health topics and contribute their experiences without needing to reveal their identity.

It's more private, yeah, it's definitely more... you know, you are able to look up safe without feeling embarrassed about if you were to talk to somebody about it. It's not judgemental. There's a support network as well. It's definitely beneficial because it's quick but only because of that, it's also because it allows you to talk to other people and brainstorm. So maybe coming up with things that you haven't thought of before. (Lara, aged 33)

Sometimes the participants 'lurked' on the forums, just reading and noting what other people were saying about a health-related subject that interested them.

Generally, I go on there just to get people's personal experiences and questions and to see the comments. I don't generally actively participate. It's more just reading them ... like if I've read an article then you go on and get people's personal experiences, you can confirm that it was accurate what the article was saying. It just kind of backs up the research you've been doing with a more personal effect. (Laura, aged 27)

Online forums and social media groups were sometimes used as a way of finding information based on lived experience that women were having difficulty accessing on medical websites or from their encounters with doctors. Diane, aged 56, gave an example of finding information for her adult daughter, who has Hashimoto disease (a disorder of the thyroid gland):

A lot of googling was discovering what this was and finding out there was a lot of people that had [this condition], and the things that made them sick. It wasn't so much that we were talking on a forum but going in and finding what people had said. Not getting involved in that, but people were able to say, "Okay, I found out that this was blah blah blah and gluten really set me off." And it was very good. Very, very good.

Other women recounted their experiences of contributing actively to an online forum or social media group. Facebook was the most commonly-mentioned social media platform used by the participants for health and medical information and exchanging experiences. A few women also described using Instagram for following fitness influencers and Pinterest for healthy recipes and fitness tips.

I follow Pilates and fitness people on Instagram. One woman specialises in postnatal fitness and she posts exercise videos to do at home, so I've watched those and I look at her account on Instagram so that's for motivation. Instagram and Pinterest and Facebook I use every day and probably multiple times a day. Maybe you can say like three times a week for health-related purposes, maybe more maybe three or four times. Ah look, I use Pinterest a lot, I haven't mentioned that app yet. I do use that a lot, mainly for recipes and fitness ideas. (Hannah, aged 34)

Lien, aged 21, has found specialised Facebook pages for women or feminists, such one run by her university's women's department, to be helpful in finding advice about health issues, particularly in relation to fertility, sexuality and contraception, which are the health issues she has been dealing with lately. As a Chinese-speaker, she also uses Chinese-language social media to connect to her friends to discuss sexual health topics.

It's like, in those groups I feel like I'm safe to talk about things, and no one's going to judge me basing on how I have sex or how I feel about my body. Also, about body image issue, because I'm – yeah, I've got parents who think – who doesn't like my body. Yep, long story. Anyway, yes, because I'm Chinese, I'm also on a couple of Chinese social media. It's a little bit – it's like Twitter. You have the rights to follow people, and you can make it private. I've got a couple of other girlfriends, and they're really helpful and we talk about a lot of things. How to – yes, mostly about birth control and periods, and HPV vaccination, and Pap smear, and other things.

In some cases, forums were presented as providing motivation to reach goals such as weight loss. For example, Julie, aged 51, said that she uses a discussion forum to support her weight-loss efforts using the '5:2 Diet'.

Well people post photos of their before and after a lot. And I've always been – well I'm not obesely overweight, but I'd like to lose some – and I've had this problem for as long as I can remember. And people say "Since January I've lost 20 kilos". You think, "Wow, that's fantastic!". And when you see their before and after photos, it gives you a lot of motivation. You think "Wow, all these people can do it and this is their proof, then I've got a chance".

For women with chronic health conditions and those caring for infants and young children, in particular, online forums and social media groups were often used as a form of lay creation and sharing of knowledge. Women with chronic conditions used online sources to help them find a label for conditions that previous medical consultations were unable to identify, thus achieving their own diagnoses. Once a diagnosis was achieved, they used the internet to find support communities or in some cases, create their own. These communities were used to keep abreast of existing knowledge (treatments, tests) on their conditions.

One example is Justine, aged 38, who lives with two chronic and severe pain conditions: osteoarthritis and endometriosis. She has found that her local healthcare services have not been as helpful as she would have liked. She has had to do her own research online and then push for treatment. Justine's online connections have been very important to her in managing and dealing with her pain.

I live on Facebook and it's actually got me through a lot of the bad times. I've been isolated a lot for the last five years. I think it's called Chronic Pain Australia, yeah, Chronic Pain Australia and then there's a local group. That's really good to get support; have other people normalise the emotions we're going through that other people put back on us that we're being irrational.

Megan, aged 48, has a chronic medical condition, lipoedema, a chronic condition mostly affecting women that causes abnormal building of fatty tissue in the limbs and buttocks and is often mistaken for obesity. She spends a lot of time online looking for information and participating in support networks on Facebook, including one that she started herself that now has almost 1,500 members. The members of these support groups share information with each other about their condition, including research papers from medical journals and relevant media articles. She thinks that these ways of sharing information have meant that people with her condition are now often much better informed than medical professionals. Megan was diagnosed a year previously and had found it very frustrating to get a diagnosis and appropriate medical treatment.

Now I only visit GPs if I need something like referrals, and I basically go in with all my research, and tell them what I need the referral for. They get shitty about that. The medical establishment do not like people who come and speak to them about diseases that they don't know about, and they do not like people who have gone and got their own education about their own health. It's very intimidating for them.

Based on her own research, Megan has developed her own protocol for how to deal with her condition, and shares this online via the Facebook pages she is involved in. She attributes the success of her own Facebook support group to developing this protocol, which has had beneficial effects on her own health and those of others who have followed it. Megan also emphasised the importance of the emotional support offered on the Facebook group she set up:

Women post about issues that they can't talk to anyone about. Then we get responses from people in the group, and I also post responses as well because I've done a lot of research into all of this, and I've come a long way too. It's a lot of helpful group support. We have a lot of suicidal women. We step in, and that's why I have an international admin team. We have someone managing the group, 24/7, and we keep an eye on those things, and basically reach out and help people where we can.

Katrina, aged 38, is another participant with a chronic illness. Her interactions with online peer communities are based on reviewing what other people say rather than uploading her own content. Katrina said that she found discussion groups helpful sometimes for information, and for knowing that other people were going through the same things, but did not interact with others on them.

I wouldn't say I didn't find it useful, but I wouldn't say I found it really useful. I think it was kind of useful in the sense that you didn't feel alone because I could see people were going through similar issues or worse, which kind of sometimes made me feel like "Oh, at least I'm not that bad!"

Sally, aged 41, has a chronic pain condition. She mentioned Pinterest as a platform that works well for her, as she can find relevant medical material. She thinks the articles about pain she finds on Facebook are not high quality. The visual aspects of Pinterest's layout work well for her, as do the opportunity readily curate material for reading later:

I find because I can just scroll past a lot of stuff I don't want, or I can just say I don't like to follow that anymore so just go away. I can pin things for later that I want to read later, or I don't have to – It's easier just to keep a little, I've got a little thing for chronic pain or parenting chronic pain. Just stuff I might look at later, I might not, but yeah.

Online discussion forums and social media – and particularly Facebook – were used by many women for finding information, advice and emotional support for parenting and promoting the health of infants and young children. For example, Focus Group 1 had four members aged 25 to 30, all of whom were part of a mothers' group for women living with mental health conditions such as anxiety and post-natal depression. Members of this group noted that they have a Facebook chat group for their mothers' group, which is used almost daily for conversing online with each other. In this Facebook group they exchange photos of their babies with each other and talk about personal issues to do with their lives and their babies. The members of this group noted how important it was for them to be part of this group, providing friendship and emotional support in a context in which they were struggling with mental wellbeing and motherhood.

Participant: *Having someone to talk to in the middle of the night who understands how excited you are that the baby finally did a poo.*

Participant: *Yeah, and it's mainly for reassurance. Because you talk to people that had had babies ages ago and they're like, "My baby always had naps for this long at this time." It's like, "No they didn't!"*

Participant: *Liar! [Laughter.]*

Participant: *"My baby always slept through." I'm like, "Oh – so they never teethered, they never had a stomach bug?" Like just because you talk to parents and stuff, like my parents and they're like, "Oh they always did that." I'm like, "Oh yeah, okay, I believe you". You know when you have everyone ...*

Participant: *Keeping it real.*

Participant: *... and you message someone and everyone's like, in the same boat. And it's funny that everyone that's had babies at the same time, are in the same thing.*

These women appreciated this contact so much that one commented: 'I feel like the Facebook, you know, like our group of Facebook mums, it's great for our baby, like checking on baby's health but it's even better for our mental health'.

For some women, online forums and social media were used in similar ways to health and medical websites: as a first source of information that helped them decide whether they needed to consult a doctor. For example, the participants in Focus Group 1 agreed that they tended to go onto the Facebook groups or other online mothers' discussion groups before seeing a doctor, as they didn't want to bother the doctor for minor health issues. They noted that it was easy to become concerned or anxious about their infants' health, and they used these groups to determine whether a symptom was serious or not.

I think it's just because there's so many little things that babies go through quickly that I'm not sure if it's severe enough, if that makes sense. Like even just things from like a little rash ... If [other group members] think it's not normal then I'll go [to the doctor]. (Participant Focus Group 1)

Social media groups and online discussion forums offered connections to others at different scales: from the very localised group for people living in the same geographical location, to national groups and often very large international groups. The participants in Focus Group 1 were members of other Facebook groups or pages, including one established just for mothers in their city, and others that had national and international membership (such as Baby Center). The size of these groups, comprising thousands or in some cases, millions of members, provided opportunities to seek support and advice from a vast group of other mothers and access a more diverse array of opinions and experiences.

It's the same kind of support but on a larger scale. So there's ladies all over the country. Whereas here, we all met through a birth centre, so we've all got fairly similar ideas of parenting. Whereas my Baby Center group, there's a bit more of the more mainstream other kind of styles of parenting. So it's good to get a comparison. (Participant Focus Group 1)

Facebook could also offer groups that may have international membership but which cohered around highly specific health conditions, health and fitness interests, or concerns or life stages. For example, one woman in Focus Group 1 noted that she had joined a Facebook page for mothers who were breastfeeding babies with allergies. A Focus Group 2 participant was also caring for a child with allergies and had found an online forum for women in this situation to be a key source of advice and support.

For me, I have a forum that's for mums with allergy kids. So I will often just go and read things on there because I find it really useful. I get lots of information that I wouldn't have found otherwise. I do often actively ask questions, but questions that just like an experienced mother would know, not necessarily medical, yeah.

Hannah, aged 34, has a four-year-old daughter who lives with an unusual severe disability. She finds also Facebook to be a key platform for engaging with other parents.

Yeah, I've done a lot reading about her condition, I use social media for that because her condition is a very rare one and there's a page or group for parents of children who have this rare disability and so we share a lot of information via that Facebook group about medications and equipment, wheelchairs, therapy, and there's a specific website for her disability and I refer to that a lot.

Rachel, aged 38, is interested in natural parenting and natural health, and said she is a member of 'ten or 15' Facebook groups related to these topics.

The Facebook one [is most useful]. Because they're connecting me to people that are like-minded. ... Like if I have a question about magnesium, I'll go to the magnesium group and if I have a question about natural parenting, I'll go to the natural parenting group. If I've got a question about vaccinations, I'll go to the vaccination group. So there's lots of little different groups in that whole big thing, but I know they're all separate.

Online peer exchanges were not always beneficial or supportive, however. A participant in Focus Group 2 commented on the 'borderline bullying' that she sometimes experienced on Facebook mothers' groups: 'There's a fine line between giving your opinion and then like pushing and pushing or being judgemental, and I find sometimes you can [cop that] on the page'. The women in Focus Group 1 also made reference to the 'fights' that could erupt on Facebook mothers' pages. Contentious topics such as breast-feeding versus bottle-feeding or the risks of immunisation was one key trigger for such disputes. As one of the members of this group commented: 'Most groups I'm in, it's agreed that you do not speak about vaccines because it will just cause a fight all the time'.

Assessing online information

While they were very active seekers of online health and medical information, the majority of participants expressed caution about its accuracy and validity, and, in some cases, expressed difficulties in knowing how to assess this information. The women described various strategies to determine whether or not the information they found could be trusted. As Audrey, aged 69, noted

Google is most useful technology – I think it's a great place to start, [but] when I do go on to Google I don't go for the first one, I give a bit of time to research all the different sites to try and get a good overview. I don't believe the first one that might pop up.

Strategies employed by women included looking for government-related websites (such as those run by Departments of Health) and preferring Australian sources over non-Australian (because they were considered more relevant).

I'm very careful to stick to Australian websites. Largely because, I've figured the fact that we're in Australia and dealing with Australian circumstances, I think it's best to stick with what's real in this country. (Suzanne, aged 62)

Well, say for instance, you were looking about diabetics you would go to the official diabetes Australia website, you would hope that their information might be more reliable than just your general research like looking on Wikipedia or something like that. (Jodie, aged 45)

There's some American sites that I end up getting sent to, I think it's WebDoc or WebMD, or something. Once I read it from there, a lot of the times it directs me to Victorian Health, so, I'll have a look at that as well. (Justine, aged 38)

Amelia, aged 24, is happy to place her trust in websites where she can tell that 'experienced people like doctors and nurses' have contributed to the content.

Websites like Tresillian and stuff I've used them a lot in the past. Well they have stuff on there in regards to sleeping, children's health. Also the Raising Children website, that's got good information on it as well. I think that's about it, they're the main two I would go to. And Mayo Clinic as well.

Other participants attempted to determine whether a website or discussion group was influenced by commercial interests, such as pharmaceutical companies.

The information has got to be based on fact only where the research has been done by a reputable organisation. If I can't find anything that hasn't got anything that rings true, I'll ignore it. The other thing is that it's very hard when it's put out by a company that's actually making money, so I tend to steer clear of something like the CSIRO and Weight Watchers. I'm a bit cynical about programs like that. (Susan, aged 56)

One of the Focus Group 2 participants said that she was advised by the child nurse to only go to websites ending with .org or .gov rather than .com, so as to avoid commercial websites that may be simply interested in selling their products: 'You know they're selling a product because they're like, "And here's a link to the product"'.

Some women were selective about the kinds of information they would principally seek online. For instance, they may look for general health information such as that on diet from online sources but seek medical attention for topics they deem to be 'medical'. Bernadette, aged 53, was one example. She said:

[The internet] is just a good place to start the research process. I'm not having to make sure I'm there at the doctor's to find out new information about diabetes and what they're doing with that and that sort of thing ... The downside would be [not knowing] how reliable the source is, depending on what you're researching, I guess. For example, for a hip replacement is something that is pretty standard and happens a lot, but information on a chronic disease – that information could be very unreliable.

Women who worked in health-related occupations were able to draw on their professional knowledge when evaluating online sources. For example, Katrina, aged 38, noted that she has training in evaluating clinical guidelines, which helps her to assess the validity of the information she finds online.

I'm pretty familiar with different types of evidence, basically, like systematic reviews and that kind of stuff. So – yep. So I think sometimes if I'm looking at journal articles then I'd probably see them as a little bit more legitimate than maybe just a website of maybe a lobby group or something like that. So generally I go for published in First World countries – those kind of journal articles. Or if there's information provided by the government on government websites or publications by government organisations then I'd probably think that they're probably a bit more reliable than anything else that I would find.

As a trained and experience allied healthcare professional, Erica, aged 55, said that she is better able than many people to evaluate the accuracy of information she finds using Google:

Well I guess I've got a little bit of an advantage in being a health professional. I look at the URL. It'll be anything that comes from a university or comes from databases that I know are credible, like the Cochrane database for example, or government websites. I'll check that out. Or I'll look at what organisation – if it's an organisation I know, if it's the National Australian Diabetes Organisation type thing. But if it's something like I don't know, I look at 'About Us', I look at the URL, I look at who's on the board: that sort of stuff.

Many participants also sought to actively evaluate the credibility and validity of the information they encountered in discussion forums and social media. It was notable that in the case of the latter sources, the 'realness' and personal nature of online forums for some women signalled authenticity and trustworthiness. They thought that the people who engaged on these sites could be trusted more than websites where there could be a possibility of vested interest and bias involved in the content. As Houda, aged 45, commented:

You get different perspectives from different people, I think they are real people, I don't think they have any agenda behind what they're saying. If you go on to a health website you think, "OK, who's funding it? What pharmaceutical company?". Do you know what I mean? I think they are a bit more honest than websites. If you go on to a breast cancer website and they promote meat, you think "OK, who's funding them?". And it's the meat companies. With the social media groups that I subscribe to, I like watching their videos, or the articles they put up because I trust the information they are giving.

Bryony, aged 25, talked about the difficulties of determining how to evaluate the accuracy and reliability of the health information she finds online. Trusting the accounts of people who had tried various treatments was an alternative to trying to discern whether commercial interests were involved in promoting some brands over others.

There were so much conflicting information and whose agenda are they trying to support as well or anyone trying to get you to buy their health supplements. You can't even discern what's actually truthful or just snake oil. You could say, "Well, I could take these supplements if they make me feel better, but you're selling this on your site". I don't know how I feel about this. I guess I would look at okay, who's written it, what authorities as well.

Anna, aged 30, said that when she began engaging in weight training activities, she used the internet a lot to search for information about the best way to train. She found that the amount of information was sometimes overwhelming, and she could spend hours looking for the exact kind of information she wanted. In terms of evaluating the information she found online, she relied on checking against other sources and looking to see how many people were contributing their experiences and what the quality of their contributions were to community discussions. Anna noted that people post their own programs on online forums and social media groups that have worked for them, so this can be useful as well.

Valuing peer experiential knowledge does not necessarily exclude recourse to the authority of medical expertise. For example, Rachel, aged 38, is interested in alternative health. She explained that she uses many Facebook groups to find information on this topic. Accessing these groups gives her fast answers to her health questions, but through selecting to ask questions in different forums she also ensures her guidance is relevant to her values. While Rachel is very actively involved in multiple online peer communities in this way, she is also conscious of their limits and does not always use this information source if she feels she needs a face-to-face medical consultation:

I've got spots on my hand, it could be dermatitis, it could be hand foot and mouth, it could be a rash, like you know, it's huge. Whereas if the doctor looks at it – "Ah yes, you have a rash." It's easy for them to see it straight away. But if you're googling stuff, or you're using the internet, or even social media for that matter, they don't know the full story and they can't see what you're talking about – it's just their opinion. But if you go to the doctor, the doctor has studied for this and they know what they're looking for and they know how to deal with it.

Some women said that they deliberately avoided discussion forums and social media groups because they did not consider the information presented to be useful. Suzanne, aged 62, for example, noted that: 'I'm very strongly against chat sites and what not because there's basically no scientific background to them. I wouldn't read an online discussion forum'.

Amelia, aged 24, estimated that she is a member of around ten Facebook groups for parenting-related topics, and enjoys participating in these supportive communities. She prefers medical websites to find health information, however.

I wouldn't trust the information, I wouldn't trust that information as much as I would trust information that's coming from health professionals. Because they're the ones where you don't know if what they're saying is reliable or not. I don't avoid them but I don't really take much on board from what I see on there ... Only because so many people can write anything they like on the internet, so it's hard to know whether what you're reading is relevant or whether it's truthful.

Apps and wearable devices

For those who used health apps, calorie-tracking apps such as MyFitnessPal and Weight Watchers and physical activity apps for monitoring heart rate, calories burnt and steps taken or providing workout or yoga programs and routines were by far the most often mentioned. Other apps nominated included those designed for the following purposes: medication reminders, self-diagnosis, medical insurance, first aid, Medicare, water consumption, child vaccination, booking exercise classes, pelvic floor exercises and sleep-tracking. Many of these apps were used for information purposes: to look up information about pharmaceuticals, for example, send out reminders or to generate details about the users' own bodies. Lara, aged 33, described the various apps she used for these reasons:

I use apps daily. Just to get pill information – so like prescription information, what doses to take, what the side effects are, which medicines you can't take together. I'm just trying to look it up on my phone while I'm talking. I also use the one that reminds me to take my medicines as well. I use home doctor app, Bupa, the first aid app, HealthEngine, the Medicare app, I have emergency ID and Epocrates is the one I was thinking of. I have one that reminds me to drink water as well so like every few hours it will be like "You have to drink water now." So now I drink so much more water.

The women who were using health and fitness self-tracking apps and wearable devices appreciated the better knowledge of their bodies that their practices gave them. They reported struggling with weight loss or attempting to increase their fitness levels. It was notable that women in their 50s, 60s and even 70s reported using apps and wearable devices for these purposes. For example, Pearl, aged 72, uses apps on her iPhone to help her monitor her weight-loss and exercise efforts. She commented that:

I think it just helps you keep track of things a little bit better and easier. Before you had all these apps and things, you never knew how many steps you'd walked or never knew whether your heartbeat was fine or not unless you went to the doctor's or the hospital. So this way it's given you a little bit more control of what your body is telling you. Or knowledge I should say, not so much control, more knowledge about what your body is doing.

Audrey, aged 69, is another example. She has also used a calorie-counting app intermittently as part of a weight-loss attempt:

I think they are a good source of record keeping. I do like the way you can look at them and see what you are eating and how much weight you did lose in that period of time. I'm not planning on losing heaps of kilos, but the goal is for losing about five or so.

The women who used calorie and fitness tracking apps and wearable devices discussed how motivating they were, allowing them to set goals that they could strive to reach.

I have an app that tracks steps. It's very good to – it's great to know how many steps you've done. It means that I'm exercising enough. It gives you help, it gives you the knowledge and ideas to get you a little bit excited. It just helps, just to be able to know that there is assistance out there. And if I know how many steps I've taken, it tells me how much weight I can lose. (Diane, aged 56)

I found the app that monitored my steps really good because it gave me an idea of where I was going and it encouraged me to use it more and get up and do things more. It was counting my steps so it just gave me a general idea of how much I really was getting up and moving about and it encouraged me to move about more and sort of set myself goals. (Denise, aged 66)

Several women also referred to enjoying the notifications and reminders that apps and wearable devices sent them, again as a way of providing motivation to reaching goals. One example is Julie, aged 51, who uses MyFitnessPal to monitor her calorie intake and physical activity:

The app lets me know whether I've done well or whether I haven't done well. Because you get a bit complacent with these sorts of things. And it sends me messages as well: "You haven't logged on for a particular amount of time" or "You haven't done enough steps today". It just prompts you with bits of information like that. So it tracks how I'm going and it gives me reminders ... Every time those little messages pop up, I think, "Oh God, I haven't done that yet!"

Among those participants who said they used a wearable device for health and fitness, Fitbit was the most highly-used. Those women who used it described the benefits of being easily able to track their physical activity or their sleep patterns, using the automated features of the device.

The Fitbit is easy. I don't have to do anything, I'll just wear it and set goals and that's it. It's easy and very measurable. It's quantifiable, there's no point in having goals if you can't quantify it and you can't measure it, well Fitbit makes both of those very easy. I wish I'd had it a lot further back. Even ten years ago, this was a dream. (Robyn, aged 64)

All three participants in Focus Group 3 (comprised of women in their 50s) own a Fitbit and had used it for tracking their steps. One woman said that she uses the Fitbit to monitor her sleep as well and wears it at night.

Yes, I know I woke up 17 times. I find it interesting to compare what I know literally happened and what this thing is telling me. So for me, that sleep bit is just out of interest factor really. I just think, "Oh!". And I try and see how accurate it is, what the other information is telling me about myself, how much do I trust that I suppose.

This woman noted that she thinks the Fitbit is accurate in tracking her pulse rate, because it seems consistent, and she therefore trusts it. She has an unusually low pulse rate, and has been tested by her doctor, and the Fitbit picks this up. Another member of this group talked about how her Fitbit helped her to increase her exercise levels and heart rate. She is trying to incorporate more running into her regular walk. She checks her heart rate levels after she exercises, to see how much she has exerted herself and whether she has reached maximum heart rate. The third member of this group described the badges and notifications she receives from her Fitbit as 'motivating'. She recounted how she sometimes decides to leave her car further away from work so that she can accumulate more steps on her Fitbit.

The habituated feeling of wearing a fitness-tracking device and reviewing the data it collects was remarked on by one of the Focus Group 3 women. This sparked a conversation among the participants, reflecting on their experiences of using their Fitbit.

Participant: *Actually, if there are days that I don't wear it, I do actually miss it now. So I've been wearing it long enough that if I go for a couple of days and I don't wear it, I actually think, "Oh, I should put that on." Because I go to look at something and oh, I haven't done anything, because nothing is registering. So now I suppose I rely on it a bit.*

Facilitator: *Do you miss it because you think to yourself, oh, I wonder how many steps I've done, or do you sort of physically miss the...*

Participant: *No, I wonder how many steps I've done and I wonder if I've walked far today, but I generally know that myself anyway. Like I know if I don't physically go for a walk, I won't achieve my 10,000 steps.*

Participant: *I find I get to the stage where I can predict how many I've done, even if I'm not wearing it. So I know if I'm at work and I haven't got it on, I have a pretty good idea of what I have or haven't done.*

Erica, aged 55, uses a Garmin smartwatch to track her running, particularly when she is training for a particular event. She likes that the device is thin and light and she can easily read the display, and it collects the data she wants (number of steps and kilometres covered). Erica said that she enjoys the buzzes and reminders that the Garmin delivers to her. She also commented on how the data collected by the device has pushed her to walk more to reach her 10,000-step goal.

If it buzzes during the day, then that's a good thing, because especially if it buzzes while I'm still wandering around, I haven't gotten to the end of the day, so I know I'll be over 10,000 steps. Actually, that goal, I'm just thinking about it, it's actually quite important. [My daughter] and I, the other day, it was two weekends ago, because we went – I took her shopping because she was getting ready to go away on this trip. She said to me, "Mum, make sure you wear your tracker, because I want to see how much we do walking around shopping". Because we want to try and hit our 10,000 steps a day. Because we were short about 2,000, we deliberately did another track around the shopping centre, 'til we got to our 10,000 steps.

Frances, aged 63, similarly commented that she has found herself doing activities like walking around the kitchen late at night 'just to get those last steps' to make her 10,000-step daily goal, so it does work as a form of motivation. She said that she has found benefits from using a Fitbit to monitor her physical activity and sleep. It has helped her to improve her activity levels and sleep quality.

It definitely makes me more conscious of it all. Sometimes – not always – but sometimes it induces me to do something about it. It's also interesting, because over time you get – you learn about how much you have to do in order to get to your 10,000 or your 7,000 [steps] or whatever, and you put that together with all the information that we hear about how important it is to move.

Frances also enjoys looking at the graphs that the app shows her on her body weight and physical activity:

So the fact that I've got a graph showing a trend is much more satisfying to me than just having a list of things written down in a notebook. I don't get wildly excited when it gives me little comments like, point two of a kilo to go and this goal is in the bag.

The coloured lights on the Fitbit are other features that Frances finds motivating:

I get a pink light – the whites flash and then there's a pink light when I get to my 10 minutes to the hour and I haven't got my numbers – haven't got my 250 steps. There's a blue light that flashes and I get a little buzz, if I get a text message or a phone call on this. That is quite handy ... If I actually get up to my 10,000 steps, you get the buzz and the flashing lights and all the coloured lights go. So you get a green and a pink and a blue. So that's pretty exciting.

Some women said that there was a social side to using their self-tracking apps or wearable devices. As Erica recounted, her daughter has a Fitbit, and they use their Fitbits together when out shopping or on other activities involving walking. Frances noted that her husband also uses a Fitbit, and she enjoys competing with him to see who can accumulate the most steps:

Occasionally I get into the competitive spirit ... not so much during the week, during the week we just do what we can, but on the weekends before we got Fitbits we would routinely have tried to go for a walk both days on the weekend – so 30 minutes or thereabouts. These days we still do that, but if something goes wrong and if there's too much going on and things don't happen and we get to, let's say dinnertime or before dinnertime and we're still short 10 active minutes, it is not at all unlikely that one of us will say, "Let's just go walk around the block to get those 10 minutes".

Emily, aged 25, said that she engages in Fitbit step challenges with her friends:

Yes, I've got lots of friends who track their steps. We do fitness tracking and encourage each other as well. We've all got Fitbits, so we do step challenges. Yeah, so the Fitbit goes on to the app and then we compare our step counts. Yeah it does it kind of made us want to challenge each other as well so it was also motivating.

Jessica, aged 24, is an active sports player and uses a Garmin smartwatch to monitor her physical activities. She reviews the data generated by the smartwatch to try and improve her sporting performance. Jessica is also attempting to lose weight and uses the MyFitnessPal app on her phone for counting calories. She uses the smartwatch and this app together to monitor her energy output and input. For Jessica, the value of being able to enact these measurements is to closely watch her energy expenditure in relation to her food consumption habits.

I think that my need to have a calorie counting app affects my health is that I know that, if I take in a certain amount of calories, I will lose weight. So for me that's very clear cut. So if I need to lose weight, that's a positive effect ... Like at the end of the day if I'm eating less, feeling lighter, I feel better, better about myself, my digestion's better.

Jessica observed that she finds the notifications she receives from the app to be 'a real motivator':

Like when I get really into, it encourages me. So, it tells you like, once you enter your calories for the day, like you say in five or six weeks, if every day was like today, you could weigh this amount and that's a real motivator. Just keep going and I'll lose those few kilos or whatever ... When it works best, when I use it to its best effect, I'll be on the app probably five to ten times a day, so it's every time I eat. I really - when it's going well, I really enjoy it.

Jessica pointed out that she also uses the app to train her in good nutritional practices, particularly to support her athletic training goals: she makes sure she eats enough protein to build good muscle mass, for example, and not just to lose weight. She sees the app as an initial stage in long-term behaviour change, but not something she will use for a long time. She noted that it is her 'attitudes outside the app' that are the most important as motivators – 'the app is just a tool'. She went on to contend that after she has used the app for while her knowledge about her body, and how the food she eats affects it, will reach a point whereby she won't need the app anymore, and eating decisions will become part of her mundane routines:

So yeah, it does definitely change the way I view it but I also know I think that the things I've learned from it are positive. And I think I will get to the stage where like all the knowledge I have about my body and what's in food can hopefully accumulate to a place where I'm in control: probably not calorie counting, just getting into a routine, the things I eat, where it becomes a habit.

Jessica also uses a Garmin heart-rate tracker as part of her training regimen.

It's really interesting, because it kind of shows you how your fitness is developing. So [playing football] is a really good example. I try and keep my fitness up as much as possible when I train and at the start of the season, I'll burn so many calories and my heart rate will be going crazy because I'm unfit. Then as you get fitter, you notice your heart rate, it can handle a lot more.

Anna, aged 30, uses the GearFit2 Samsung wearable device to track her sleep, body weight and heart rate. She likes the fact that she can wear it all the time, except when showering. She reviews these data with other details she records about herself or just notes mentally, such as the medication she takes.

I'm a bit of a data nerd. I just like seeing all those little correlations and then also the different types of medication, how that affects my behaviours as well ... Sometimes I'll put a note in my calendar to say, I started this medication here, started it there, finished it when, blah blah blah. Then see if anything changes – specific hormones, oral contraceptives and stuff like that. I find that I have a very weird weight fluctuation with that, and also it does affect my sleep. That all just ties in as well.

Later in the interview, Anna went on to mention that she noted from the data she collected about her weight that when she went off the pill, she lost two or three kilograms. She wouldn't have realised the impact of the pill unless she had been monitoring her weight and relating it to her contraception medication. She mentions that she can now also monitor how the medication she takes for sinus infections, which she frequently experiences, affects her sleep. It is important to her that apps are free, because she doesn't want to risk spending money on something she doesn't use. She also looks for a single sign-on and apps that are easy to use.

Anna says that she finds it comfortable to wear her device while she sleeps.

You get used to the way, you get used to the feeling of it, and it's just like wearing a watch. The only thing is that every time I get a phone call it vibrates, but you can turn that on and off. Yeah, it's pretty good to use. You can just set it and forget which is really important to me.

She also likes the fact that she doesn't have to remember to turn it on, as it is always on her wrist and always automatically tracking. She has organised her training apps so that they will be easy to use as well: 'If I'm starting a run and turning my music on and I put the app in a folder, where everything is all together, then I just go bah bah bah, on, on, on, that's it'.

In terms of sharing health-related information about themselves, few women who were engaging in self-tracking said that they shared these self-generated data with their doctors. No women engaged on 'social fitness' platforms like Strava to share their self-generated physical activity with other self-trackers. Some women said that they sometimes mentioned their self-collected data to close friends or to family members. Some reported a little 'friendly competition' with their partners, other family members or friends who also used digital self-tracking devices, noting that this helped them with motivation and enjoyment of the practice.

Several women used period tracking apps to help them identify patterns in their menstrual cycle and generate notifications about when their next period could be expected.

The main app I use is a period tracking app. It's called Clue, and it's helpful in knowing when I should be expecting my period and things like that. It's easy to use. I have a lot of friends that use it. It looks good, yeah easy to use. And it's helpful. (Ashleigh, aged 22)

Many of the participants who had young children had used apps for tracking the progress of their pregnancy and finding information (apps such as Ovia and What to Expect When You're Expecting) child vaccination records, infant development monitoring (in particular, the Wonder Weeks app), and parenting advice (for example, Baby Center). These apps served a combination of information provision and generating new data about the infants' health and development. For example, the participants in both Focus Group 1 and 2 talked about using period and ovulation tracking apps when they were trying to conceive, and one woman noted that she was going to start using it again to track her menstrual cycle. Other Focus Group 2 participants added that when they were pregnant or trying to conceive, they spent a lot of time monitoring their health. One woman described how she became very focused on using an app for this purpose:

I was very – not now – but I was very diligent with recording my health when I was trying to get pregnant. So, you can use an app to record, like, literally daily symptoms of, like, put in your period and then all kinds of – if there's any signs of discharge, if you've got a temperature, you put in all of your details and it tells you when you are at your most fertile. I got a bit obsessive about it. I didn't know – I was told that I wouldn't be able to fall pregnant, so I was like obsessively putting information in and checking it. And I don't think I would want to use it again, because it was a bit – I was a bit addicted to it.

Some women in this group mentioned using pregnancy apps, including those that showed the size of the foetus as it grew, comparing it with fruit. They also liked this app because it included discussion forums for women who were in similar stages of pregnancy. Another woman said that she had used the Glow app during pregnancy, but now that her baby was born, she preferred the local information provided by her Facebook mothers' group:

I haven't used Glow since having [my baby], because I found a lot of information was very much American orientated and that was bit limited – and the Facebook one tends to be local mums in the area as well.

Using apps to track the health and development of their children was also common among the women in the life stage of mothering infants and young children. Amelia, aged 24, explained how she used the Baby Center app to monitor her children's development. The age of the child could be input into the app so that customised notifications were generated, against which she could compare her child's achievement of milestones:

The Baby Center app gives you milestones in your baby's development so something that you think might be a health concern might not be because it might be just a normal developmental thing that they're just going through in that particular stage. But I guess I use it more for the developmental milestones side of things but it can be related to health. Yeah, because you put in the baby's birthday so it tells you exactly what should be happening at each stage. Same as The Wonder Weeks app – I use that as well for tracking development.

Some of the women in Focus Group 1 said that they used apps to track the habits and routines of their infants. They had a conversation in which they talked about apps for tracking feeding, nappy changes and sleep. They said that they found these apps helpful because 'we're still new mums', as one woman put it, and 'you're just so tired all the time' as another added. A participant in this group went on to note that apps for tracking their babies can be helpful when they are dealing with trying to note the routines and behaviour of their babies:

You're thinking about so many different things, it's so easy to forget to look at the clock when they get up from their sleep. Or yeah, to pay attention to the clock. So it can really help if you're like, "Why are you cranky? Maybe you're tired?" ... So it gives you that information that you might not have kind of been able to keep track of yourself.

Several women also used the Wonder Weeks app, which provides information on the cognitive development of infants and how this affects their behaviour. The women found this app reassuring, as it helped to explain why their infants may be particularly unsettled:

Participant: *So I don't have the notifications on it or anything, but if she's been real crazy, shitty for no apparent reason, sometimes I'll check that and be like, "Oh she's going through a developmental leap this week and I don't have to worry about it – she's okay, so she's not sick or anything, she's just having a mental growth spurt". Which is great.*

Participant: *Yeah, it's reassurance isn't it?*

Participant: *Yeah, it's reassuring to be like, "Oh!". And it makes sense because they change so much!"*

Participant: *It's happened to me a couple of times, where I just genuinely do not know what's wrong with this child. And then you're thinking, "Is she teething, is she sick, is there – is she constipated?". Then you'll [think], "OK, well she's going through a leap so that is probably the reason".*

These group participants went on to describe how they were 'offloading information' from their brains to the app, 'so you don't have to rely on your brain so much'. One woman said that if she went to a child health centre for her baby's check-up and was asked how many nappies she went through a day, she could pull out her phone and check it on the app. They even described inputting these data in the middle of the night, when changing or feeding their babies, or first thing in the morning. Participants in both focus groups with young mothers noted that that they spend far less time thinking about their own health or searching for information about it online, as they are currently preoccupied with their infants' health and wellbeing. As one woman in Focus Group 2 explained:

I know if I'm not feeling well, whereas with [my baby] I don't know. Is he just being a baby or is he unwell? Is there something wrong? Whereas with myself, I know if I've got a cold or whatever. So it's much more about him than about me.

The limitations of apps and wearable devices

While health and fitness apps and wearable devices were useful and helpful for many women, the participants gave several examples detailing the deficiencies of these technologies. They had encountered problems in successfully using the apps and wearable devices that centred on such issues as poor design, lack of accuracy or failure of the technologies to produce promised or expected outcomes. Even those who had used self-tracking apps and wearables for some time could become bored, or disliked the constant notifications they received.

For some women, the apps they had attempted to use were not automated enough, and required too much time and effort to use, or did not provide the appropriate categories for self-tracking. Anna, aged 30, gave up using a food tracking app for these reasons:

I've tried using one that lists the FODMAP diet, but it was just – it didn't have all the foods that I normally eat, or it had foods that weren't normally available to me. I was just like, nah. It was too fussy.

Audrey, aged 69, said that she has periods when she finds her calorie-counting app to be boring and loses interest and motivation in using it:

I go in stages, I was using the health one for about 6 weeks every day, and I'm just not using it as much at the moment. I guess I was on it to lose weight and I sort of feel like it was all a bit tedious and I stopped using it ... The app at times can be not helpful, if it's a bit monotonous or tedious having to put information in to it.

As noted earlier, Frances, aged 63, is a keen Fitbit user, but she described some things about this device that annoy her. Frances likes the slimness of her Fitbit but would prefer not to wear it to bed to monitor her sleep, as she doesn't like the intrusive feeling of wearing watches or other devices in bed. She said that she finds the notifications to get her moving to be 'irritating', as at work, which is in the public eye, she is not always in a situation where she can simply get up and move around each hour. Frances also noted that when she first got her Fitbit, the calorie counter was based on American processed food, such as donuts or muesli bars, which was useless to her because she hardly ever ate that kind of food. Now a Fitbit allows users to enter fruit and vegetable servings, but according to Frances, this requires too much time and effort.

Megan, aged 48, said that she tried using MyFitnessPal for a few weeks to keep track of her diet, but then gave it up. Like Frances, she found the American food brand details in the app to complicate her efforts to record her food consumption.

I found it really annoying, so I don't use it anymore. My mobile phone died, and I had to download all my new apps and start again, and I lost all my data on it, and I couldn't find my password, and I had to create a new account. Oh, it was a real pain. That was really annoying. Also, a lot of the stuff in MyFitnessPal is American-oriented, and I just found that really annoying, that I would have to trawl through American brands and that sort of thing.

Bryony, aged 25, discussed her use of a pedometer app. She observed that while she enjoyed the positive feedback she received when she first began using the app, as she became less active and received constant reminders of this, her interest waned. The app's notifications became annoying and demotivating.

It's like, yeah, so that's why I probably wouldn't use an actual tracker. I mean, when I used it a lot, the pedometer a lot, I was like, oh yeah, I made it past my walking goal. Well done. I felt pretty good about myself. But it's like, well I don't know how much of a difference it was making. It was just like, okay, I get a nice gold star at the end of it. Then it will still remind me, it's like, "Oh, you are 64 minutes less active than you were last week". It's like, you said that the last time. How am I getting less and less active each time? ... It was just like, oh well that's lame and here is your weekly summary which I don't even look at, because I know it's not going to be great. Yeah, at the beginning it was interest because it was like, oh cool, like I've actually managed to do all of that. It was like kind of great to see – this is what I've accomplished. Then I think as my life got a bit busier as well, I was just like, meh, didn't really care too much about it. It's just always like, always reminders, yeah you could always do more. It's like, I am aware of that – I do not need this app reminding me. But I'd rather not be reminded right now.

One of the women in Focus Group 3 said that while she had used her Fitbit in the past, she no longer wears it as it had become less helpful.

When I got a Fitbit, because I had had this red line where if you sat around too much the red line came on, "Oh, make me do stuff!" But I don't know. I don't have the right kind of phone so I can't sync the information to anything, so I found it kind of a bit annoying. It could really could only count my steps and it wasn't very accurate.

One of the women in this group said that she is frustrated when her Fitbit doesn't record her exercise, such as pushing her grandson on a swing, or pushing him in his pram.

I still don't trust it 100 percent ... I don't know if it's my arm is not swinging or whatever, so I can do a whole walk and it hasn't registered. But I can also weed, and it registers. So there's time that you just know it's not accurate.

People using self-tracking apps and wearable devices are not always supported or encouraged by their friends. Jessica, aged 24, for example, said that she has found that her friends tend to be dismissive of her use of a calorie-counting app, as they see this practice as evidence that she is overly preoccupied with controlling her body weight.

I think there's a real stigma about calorie counting. It's like a bad thing and it means like maybe how to lose your self-esteem or you're preoccupied with the way you look or you're not happy within yourself ... So people are like, don't be silly, you're not fat and you're beautiful and you don't need to worry about any of these things.

Jessica commented that her friends also criticise her for using an app for calorie counting because they think that this practice is not sustainable, and she will eventually give it up and regain any weight she has lost. She went on to observe that:

I know it's not sustainable. I can't count calories for the rest of my life. I need to be able to make good decisions even if I don't feel like I have control of the situation, I know that.

Lien, aged 21, said that she uses apps for various health-related purposes, including period tracking, step counting and sleep tracking, as well as a contraception reminder app. Lien commented that the period and contraception trackers have been useful because 'they help me organise my life'. However, she doesn't like the stereotypical pink and purple colours that all period tracking apps seem to include, as she has hated those colours since she was a little girl. She has also found that the free period tracking apps don't work very well, so she is forced to pay small regular amount for one that works best for her needs. Further, Lien said that she dislikes the built-in commercial features of many free period tracking apps, which again represent users as stereotypical female users who are interested products such as makeup and shopping: 'Just kind of reminds you, what females are supposed to be and supposed to shop. I don't like it.'

Lien took up use of the sleep tracking app because she had been experiencing sleep problems for over a year. It was given to her by a good friend, who thought it might help her with her sleep. Her doctor also recommended she try one to establish what her sleeping pattern was. The doctor checks her sleep data when Lien comes in for a consultation. Lien found that using the sleep tracking app was counter-productive, as she was highly aware that it was tracking when she fell asleep, which detracted from relaxing:

In terms of falling asleep, I think it actually pressures me a little bit. Like when I'm having a late night, when I'm trying to go to sleep at 11 or after 11, and I was having this pressure of, I have to fall asleep, I have to fall asleep. I don't think it actually helped, when it comes to falling asleep.

Lien said that she doesn't check her step counting app very often, but sometimes does so to see whether her sleep patterns are affected by her exercise levels. Before using this app, she tried a Fitbit, but didn't find it helpful: 'I stopped using it because I didn't find I felt more incentive to walk more or whatever, so I stopped using it'.

While health and fitness tracking apps and devices were effective for some women, others said that they lacked the interest or opportunity to use them. Joyce, aged 73, is living with debilitating pain. She said that she has no desire to try to track her physical activity levels:

I can't do any fitness: my knees are not the best at the moment and I've got sciatica and I'm hobbling around everywhere. So a fitness tracker is the last thing I would want.

Sally, aged 41, who lives with a pain condition, has found that while using a pain recording app has been somewhat helpful, it does not really meet her needs. She commented that even when she used it to record details of her pain to share with her doctor, the doctor was not interested in these details. There is also the problem that it is painful to use the app, which requires manual manipulation, and that focusing too closely on pain symptoms can exacerbate the pain. A similar app that could work with voice commands would be much easier for Sally to use.

If I could just talk to it and it would go in to the different areas, then that would be easier. Particularly if you're in lots of pain, because if you're in a lot of pain, you're even light sensitive.

Louisa, aged 30, also managing chronic pain, has tried using a pain management app, but it wasn't useful, as it didn't cater to the different sources of pain and their changeable nature:

It was good in a way because it was like you could actually see the pain, but it was kind of bad too, because it only had a daily thing and it was like – like I had migratory pain, so I might have knee pain at 9:00am, but then at 9:15am, it's in my shoulder and it was hard to record that because it'd be like, what pain did you have today? I'm like, well, I had my knee, I had my shoulder, but I didn't have it all, all day, I had it all in different spots all day. Some hours I don't have pain – well I have pain all the time, but like severe pain, I don't have it all the time, sort of thing.

Women who had high caring responsibilities were also less interested in using self-tracking apps and devices due to changing priorities and time demands. For example, the women in Focus Group 1 said that since having their babies they had given up using fitness-tracking apps or wearables for their own body metrics because their attention has been diverted to their infants' health and wellbeing. One woman noted that she had de-activated a fitness tracking app on her phone because she kept receiving notifications from it that she had not reached her goals, and she simply wasn't able to engage any more. Others agreed that such apps 'make you feel bad about yourself' or 'guilty'. One participant suggested that there should be a 'baby option' programmed in the app ('like holiday mode') that changed expectations about step counts or calories expended for new mothers. 'Like he's having a clingy day today. I could barely put him down this morning. As if I'm going to get 10,000 steps!'

These women also commented that they didn't want to track their sleep, because it would simply be too confronting to document exactly how badly they slept when they were disturbed by the needs of their infants. As they found it difficult to eat meals at regular times and to ensure they were eating nutritious food, these women also didn't see a reason to track their own food intake. They felt as if they had not yet 'had their body back' and it was difficult to return to the same kinds of fitness routines or eating habits they kept up before becoming pregnant. As one woman remarked:

I'd like to be able to go out for runs in the morning like I used to, but I can't, because most of the time we're still asleep, because that's his best sleep, around 7am. Then I can't leave him at home and I can't go running with him. So I don't go running.

Similar comments were made by the women in Focus Group 2, who discussed how they used their fitness tracking apps or wearables much less often now that they had their infants to care for.

Participant: *I had an inbuilt activity tracking app on my phone and I had to turn those notifications off because it would be like "You haven't reached your goal, you haven't reached your goal!". So I stopped it.*

Participant: *I get frustrated with the Garmin [smartwatch], because I wear my watch during the night so it tracks my sleeping as well. Then it gives you like an insight, so a little note will pop up and you know whether your sleep has been really regular or you've had irregular sleep. I wish that there was a thing that during pregnancy where that I could put in and say I'm pregnant, because I got those notes that your sleep is really irregular, and I was like, "Because I'm pregnant!". Now I'm getting up to breastfeed, so it should be irregular. It's almost like it's shaming you – "You're not sleeping very well".*

Participant: *We have bathroom scales that tie into the Fitbit thing. So you put your weight and body mass index and stuff into the Fitbit app which used to be awesome when I was doing steps and weights and all this, but now they just don't – you look at your app and according to that I'm obese. The breastfeeding adds a couple of*

percentage points to that all by itself and you have to remind yourself that, you know, what's 'normal' for a woman is not actually my current health.

Participant: *For me, it was I wish you could put in that you're pregnant or that you've got a newborn baby and that changes things.*

My Health Record

The Australian government's Australian Digital Health Agency is working towards its goal of enrolling every Australian in My Health Record, its national electronic health record system. However, despite their generally highly engaged use of online health and medical sources, awareness and use of My Health Record was quite low among the participants. When asked if they had signed up to My Health Record, only a third (24 out of the 66 participants) answered that they definitely had enrolled themselves. The remaining participants were divided between women said they weren't sure or couldn't remember if they had registered (nine participants), those who said that they had not heard of My Health Record (18 participants) and those who had made a considered decision not to sign up (15 participants).

The women who had registered for My Health Record said that they had done so because of the benefits they could see of being able to have a digital health record that could be shared across providers. They mentioned situations such as moving to a different location or different healthcare provider, or not having a regular GP as reasons for enrolling in My Health Record:

It's harder and harder to source an appointment with a doctor when you want to go to a doctor, so if you had the capacity to just go to any doctor and you don't have to sit there and tell your story over and over and over again, I think that's a wonderful thing really. (Sandra, aged 55)

None of the women who had registered for My Health Record made any reference to the opportunity to be able to view their health records themselves or add to them. As this suggests, there was little awareness among the participants that My Health Record had been initially designed as a patient engagement tool as well as a platform for storing their medical information and sharing it with their healthcare professionals.

Some women said that they were interested in signing up to My Health Record and but had not got around to organising it yet or simply did not know how to do it. One example is Marilyn, aged 67, who said that she was in favour of eventually registering but had not done so, 'probably because I don't know enough about it. I'm not sure how to go about it and I'm not sure what it is they would need to know and how much time it would take'. There was some confusion expressed by participants about how the system worked and how to participate in it, or observations made about the complexities of enrolling. The problem was not just My Health Record itself, but the MyGov platform on which it was hosted. Several women made reference to other services on MyGov being difficult to access and use:

Yes, I have registered. I think I had to do it last year. I mean, I find the government departments of Centrelink and Medicare just the most difficult to use. Even when you call them it's just the most difficult place to access. So I really don't know. I know I'm signed up for it but that's it. (Julie, aged 51)

A common observation among women who had signed up to My Health Record was that the system was still not functioning adequately. Katrina, aged 38, has experience in medical records in her job and commented that her knowledge from her work has highlighted the deficiencies in the system. She hasn't registered yet because she wants to wait until My Health Record is working effectively:

I just kind of want them to get it sorted before I do. I just don't feel like they've got it right yet and I just don't feel like it's at a point where it's actually useful. I don't feel like it's at a point where I could actually go in there and look at the things I want to look at.

Justine, aged 38, said that she registered a while ago, but has not found that any information has been uploaded to it and has given up bothering to check:

I haven't logged in to check any of that for ages. When I did, there was no information for me to read off it from my doctors. I don't know if I was meant to be able to have access to my records or not, but there was nothing, only my details that I've put in. It was just like a system created that did nothing.

Several participants said that they regularly had to remind their doctors that they had a My Health Record, only to find that the doctors were not using the system or uploading information.

Recently I had something happen with my health where I was being contacted by a few different doctors because it was over the long weekend and so there were only certain places were open at certain times. So, I saw three or four different doctors for this one problem and they were like, really struggled to communicate with one another. Which is weird, because I'm on the My Health thing so surely it couldn't have been that hard. (Jessica, aged 24)

A small number of women had made the choice not to register because of their general feelings of disillusionment with the healthcare system or other government services. These were women who were living with chronic health conditions for which they had struggled to find orthodox medical support or effective treatment. One of these participants is Megan, aged 48. After years of attempting to access good medical care, and finally resorting to online information and peer support groups, her general cynicism towards and distrust of medical practitioners have shaped her perspectives on My Health Record. For Megan it is simply just another part of a healthcare system that has failed her:

I signed up for it, but it seems useless to me. I was coaxed into signing up, one day, in a Medicare office. But I've been given no further information about it. I don't know what to do with it. I don't know who's putting my stuff in. Now because I'm a bit cheesed off with the healthcare system, and its utter bloody neglect, I can't see any point in that. I think a lot of the medical profession don't know what the hell they're doing ... So I don't have any faith in My Health Record at all. I can't see how it would help me now. I'm helping myself.

Another woman with a chronic health condition, Justine, aged 38, thought that the government doesn't care enough to properly implement My Health Record:

I really don't think they care. If it's benefiting us, they just need to spend money because the budget comes around each year. They need to go, look, we've spent this amount of money in our budget and we've made this. If they did an audit on all these services that are actually working, it's just going nowhere. There's not one service that has streamlined the care of the Australian people that's effective. Not one works.

Some women noted that they were in favour of My Health Record, but not registered because they did not see the relevance of it. One example is Frances, aged 63, who was not sure if she had ever registered. She noted that in any case she did not see the point in having a My Health Record, as she always sees the same doctor:

I'd have to say, one of the reasons perhaps that I haven't even really thought about this is that basically I've been going to the same practice for 40 odd years and they've got the files there. If I see a specialist the stuff goes back to the doctor.

In the accounts of those women who had chosen not to sign up to My Health Record, there was a strong current of distrust in the government to adequately protect the health and medical information stored in the system. This distrust tended to relate to the women's views that the government was ill-equipped to protect people's data adequately, rather than concerns that it would deliberately exploit their data by selling them to third parties. At the time of the interviews and focus groups some well-publicised personal data breaches, disruptions and hacks, including of Australian government-held information, had occurred. Several women referred to these when recounting their caution and noted that they had difficulty trusting the government to protect their medical data.

I don't want everybody knowing stuff about me and I don't think it's safe ... Well they hacked the government census website and I don't want my personal information, like my name, my age, my address, what diseases I have, just to be public knowledge. (Rachel, aged 38)

I personally don't think the government would do a great job of securing that sort of information. They haven't done a great job on some other things, so can't imagine them doing a great job with that either. (Bernadette, aged 53)

Louisa, aged 30, commented that she views government workers as lacking the skills and knowledge to adequately protect people's data:

In some ways I'd like to think you could trust the government, but I don't really think we can. The fact that most people in the government are flat out even turning on computers concerns me pretty greatly. Like I would prefer in some ways a private business that uses really good IT security group because I know hackers, like if it was run by them, I'd be like, well if they're running it, they probably know what they're doing, it's secure as possible. They're going to employ people to test it to see if anyone can get into it sort of thing, whereas the government is just – they just don't know what they're doing.

Women who were employed in professions involving dealing with personal medical data or digital technology systems drew on their professional knowledge in evaluating My Health Record.

I'd like to know a little bit more about how the data is being protected and who's going to have access to it. I think it's a good idea, especially for people who are going to the doctor all the time and are getting prescriptions and things. The trouble is there's a certain amount of – I work in IT – so there's a certain amount of [trust] where people say "Well, everything is basically protected". Well no, it's not. (Susan, aged 56)

Beyond the digital

While digitised forms of information were central to supporting the health of the participants, they continued to nominate medical and other healthcare professionals as important sources. As noted earlier, the women's online information-seeking practices were frequently described in terms of a preliminary search that would help them decide whether to seek medical attention, rather than as a substitute for visiting a doctor. They wanted to avoid the time and effort (and in some cases, expense) of seeking medical advice if it was not warranted. However, doctors were still considered to be key authoritative sources of information, particularly if women needed a definite diagnosis, they were concerned that symptoms were serious or if they wanted to be referred for tests or to see a specialist.

While women were actively managing their own health using different information sources, they were aware of the limits of their health knowledge. Several women commented about the risk of finding information online that would cause unfounded anxiety. They viewed visiting the doctor as the way to avoid this. Emily, aged 25, noted that while she would go to the internet first for health information, she considered doctors to be the most important source of information: 'Because Google could tell you that you're dying or have brain cancer but really you just have a bad flu. So I just tend to trust that the doctor's got a bit more knowledge than me'.

The participants' frequent recourse to websites for health information did not diminish their trust or faith in medical expertise. When they were asked to nominate their major sources of health information, doctors and other healthcare professionals were mentioned by all the participants. Most women acknowledged that online sources supplemented rather than replacing the expertise and advice of medical practitioners. This was particularly the case for GPs who the women had been seeing for years, who knew their medical history well. In the face of all the information that could be sometimes difficult to assess and navigate online, medical professionals were considered to be able to use their expertise to make sense of it.

Well obviously, when you go to the doctor you're going to get a more definite opinion about something. I googled a little bit, so I went to the doctor and within 15 seconds he said bursitis straight away. So that was pretty convincing for me. So I went on to have ultrasounds and the cortisone injections. So if you want a definite opinion and you want it to be right as it can be, you go to the doctor. (Julie, aged 51)

If it's something I'm more concerned about I'll go to the GP for the assurance. Yeah, the GP and my family. I guess because there's so much online you don't know if it's true or not. I don't like to rely on it too much. I guess he's always quick to diagnose something and knock it on the head before it becomes worse. I guess that's why; you know you can trust them. They know what they're doing. Like I said, I've been going to him since I was a baby so it's been like 24 years so I've got that trust. I think that's important to have with a GP. (Amelia, aged 24)

Rachel, aged 38, noted that she valued the more personal approach she obtains from a doctor's visit. Doctors can examine her closely and draw on their experience in making a diagnosis. This expertise is not offered on the internet.

The internet's not personal. What my symptom is, I've got spots on my hand, it could be dermatitis, it could be hand foot and mouth, it could be a rash, like you know, it's huge. Whereas if the doctor looks at it – "Ah yes, you have a rash". It's easy for them to see it straight away. But if you're googling stuff, or you're using the internet, or even social media for that matter, they don't know the full story and they can't see what you're talking about it's just their opinion. But if you go to the doctor, the doctor has studied for this and they know what they're looking for and they know how to deal with it.

When they were describing their use of online sources, women expressed their view that their doctors were not always receptive to the idea that they were actively engaging with online information, and therefore chose not to disclose what they had learnt online when discussing a medical issue with their doctors. Some reported outright hostility from their doctors concerning their online information activities. A small number of women, however, recounted partnerships with their doctors in which the doctors recognised the value of the women's active engagements online. This was particularly the case for women with chronic health conditions who both consulted frequently with their healthcare providers and were very active in their online engagements, including with other patients with similar conditions.

Sally, aged 41, said that she uses often online medical sites often to research medical issues – she mentioned WebMD as her 'go to' source of information. If a medical problem persists or if she has received some test results that requires interpretation, she then visits the doctor, and sometimes find that she and her doctor both research the problem together on the internet in the doctor's office.

If I've got a report back and I don't understand a term and I've looked it up [online] and I've talked to my doctor and she looks it up, and goes yeah, that's kind of what I understand by that as well, and I think this does pertain to you, or no, maybe that's just completely wrong and we need a second opinion. It's just a way of talking about the health issue at hand.

The participants were highly aware that they needed to be careful about the quality and validity of the health and medical information they were finding online. Some mentioned the importance of verifying information with a doctor before making a decision about their health:

Google is not where you should go, you should go to the doctor first and ask them because you could get something that you see on Google and think, "Oh well, I haven't got cancer, I won't go to the doctor, everything's okay" and it's not. So it has its own dangers. (Margaret, aged 73)

Oh well of course you hear, they warn you not to take everything implicitly, not to believe everything you see [on the internet]. I use my own understanding of what I'm reading I suppose. Because I'm not – it's nothing to do with medications or anything like that it's just an understanding of the problem. You let the doctor guide you with the medication. (Diane, aged 65)

The women's recourse to medical advice depended on what symptoms or health issues they were attempting to find information about, as Rachel, aged 38, pointed out:

If it was a medical problem, go to the doctor. We've got a very good relationship with the family GP, and my daughter's specialist. If it was something that was just more of a general interest or a bit of a fad thing, if people were doing a fad diet or a certain exercise, that kind of thing, I would just go to the internet for that ... I mean you can't really compare the internet to a doctor. Like you can if you came down with chickenpox, but if you were looking into eating fermented foods. For that I would definitely go to the internet because there's information and videos and whatever, but if I thought my child had the chickenpox I would go to the doctor, I wouldn't go to the internet.

For a small number of women living with chronic health conditions, online information had superseded face-to-face medical expertise. They now relied on doctors mostly to generate an official diagnosis and prescribe tests. One example is Justine, aged 38. She commented that she has found online research very helpful due to inadequacies in her treatment with practitioners, but her doctors have discouraged her from information seeking in this way. She said that getting to the bottom of these issues resulted directly from her own research and pushing practitioners for tests to investigate.

[Doctors] always say don't use Dr Google, but you know what, it's helped me immensely. I have no high regard for the medical [profession]. Yeah, but I still have issues where I have to rely on them ... I don't go in thinking well you must be an amazing person because you have a degree.

Another example is Megan, aged 48. As described earlier, Megan lives with lipoedema. Her dissatisfaction with the mainstream medical engagement with her condition drives her own information seeking/sharing. Megan described doing a lot of online research, and also very actively participating in support groups on Facebook, both sharing and receiving information on her condition in the form of links to research, papers, journal and media articles.

After I received my diagnosis, I looked at what I could find online, and because there just isn't enough medical support for it in Australia. I realised that there really wasn't a lot out there to help me. I quit my job, and basically decided to turn myself into a human guinea pig to see if I could find my own treatment based on all the different research papers that I'd read and that sort of thing. So, I did. For six months, I read everything that I could find online, and worked out some wide-ranging treatment protocols. I got on top of the disease.

Megan is able to share all the information she has curated through her online searches on her Facebook community, thereby establishing herself as an authority in her own right. She said that she only goes to a doctor now when she needs referrals, and in these appointments, she requests what she's after rather than asks for advice. Megan observed that while her general practitioner was willing to work with her as a partner, other doctors have found her 'empowered patient' approach more threatening. Megan is an example of a 'digitally engaged patient' who has crossed the line for many of the doctors she consults. She has become too empowered and too challenging of traditional models of medical authority. As a result, she experiences antagonism from most of the general practitioners she has consulted.

Face-to-face encounters with friends and family members also remained key ways in which the participants sought advice and support. The women described discussing health matters with friends and family members and exchanging experiences and information with them as part of social encounters.

Especially when it came to the kids. I'd talk to other mothers, my friends about, you know, if their child had had that particular illness. If they were sick at the time what kind of things they did. (Hannah, aged 34)

There's a lot of information out there, where sometimes it's hard to work out what's right and what's wrong so it's always helpful to find out what other people have done or found in the same instance. So, for example, alternative therapies for the Asperger's syndrome. I found out from my next-door neighbour about getting the level of lead tested in my son to see if there was evidence of it. (Susan, aged 56)

Marilyn, aged 67, gave an example of the way in which her face-to-face discussions with friends had led her to seek further medical help for what turned out to be a serious medical problem:

With the stroke I had in my eye, I kept thinking that my glasses were dirty. I kept cleaning my glasses, it was like there was something smeared on the lens. And then when I discussed it with a few of my friends at a coffee morning they advised me to go to the optometrist and see what they thought. The man at the optometrist is a retired ophthalmologist and so he sent me straight to emergency and that was sorted from there another man in my retirement village who had a similar thing. I then made my arrangements and I'm seeing that same neurosurgeon tomorrow.

Paula, aged 36, described talking to her mother and other older relatives and receiving advice from them because they had dealt with similar problems.

Mainly because they're older than me and they know more. And they've experienced stuff themselves, like, whether it's health related issues, like pain management – my mum's got issues with her back – so she helps me with pain management, exercise, and that sort of thing. And yeah, she's kind of my doctor before I go and see my doctor. So she gives me an idea of what I might have and I usually present that to the doctor and he says yes or no. And my aunty and uncle are pretty much the same with that kind of information. They're right there when I need them. If I'm not seeing them I'm on the phone and I can ask them if I've got an illness that may have gone back through the generations of the family, and what I need to look out for as well.

Sally, aged 41, said that, on the whole, her support network of other people with chronic pain is more useful in many cases than doctors or medical websites or using Facebook or other social media sites.

I find that especially the groups that have people living in chronic pain for a long time, have done a bit more research about what's going on and talked to researchers, or talked to pain specialists who are a little bit cutting-edge.

Sally noted that 'I've never really like computers', and her pain condition means that it is difficult to use devices like smartphones because it is too painful to manipulate them. She also finds Facebook a rather superficial way of communication.

I'd rather go talk to someone. I'd rather go to a meeting, drag myself out there, I can understand it would be very useful for someone who can't drag themselves anywhere to have that link to the outside world. But I'm finding Facebook even contacting friends is not so useful, because it's just postcards of happy days that you had, not actually deep and meaningful anything and I'm getting a bit bored of it.

For support, Sally finds that the local chronic pain support group, which regularly meets face-to-face, has been the most helpful. It is the locally-specific nature of the knowledge they can share which is particularly helpful:

They're very useful because they link you to local people, local GPs that are good, local specialists that are good, local programs that are good. Help you figure out what should I do here, should I be doing hydrotherapy, should I be doing physiotherapy, should I just go home or sit and watch TV ... So yeah, there are a lot of good websites that I've looked at for pain – they have got lots of great resources and things to read, with chats and sites and all that. But it doesn't help me if I want to find a good GP, or who's good round here.

Sally has a young son and noted that she also sometimes searches for information about illnesses that he may have. Here again, however, she finds that the information about her son's health that is most valuable is what she shares with her peer network of mothers, often in face-to-face situations like chatting at the school gate at pick-up time, or through phone calls or text messages. It is the local nature of this information that is most valuable for Sally: knowing what illnesses are going around the school, for example. She also uses the local pharmacy as a source of information, bringing her son in for a diagnosis.

I suppose with my son, there's lots of friends, mothers and stuff, and usually whatever he's got, everybody else has. We just chat and exchange information that way. It seems to work a lot better than anything else, because it's very local.

Some of the women noted that they were themselves trained in health-related professions (for example, as nurses or midwives) or had partners or relatives with medical or allied health professional training and were therefore able to draw on these sources of medical knowledge. One example is Sharon, aged 59. She said that when she had been diagnosed with high blood pressure, she had sought advice from her sister, a naturopath and herbalist, as well as searching online and visiting her doctor.

When it was diagnosed, which was probably about five years ago, then I researched as much information as I could online, and spoke to my naturopath, my sister, about that as well as the advice from my medical practitioner, just so I could learn anything further that might help me.

Laura, aged 27, also referred to friends and family members who were health professionals as her most trustworthy sources of information and advice.

Probably my friends which are nurses or my auntie is a nurse because they're in the industry, so you know it's reliable information. They're personal friends and I can trust them and because they've worked for a period of time in hospitals and medical industries, so you know that they're honest about it. If they don't know they're not going to make something up.

Future digital health technologies

After having discussed the kinds of digital technologies they were currently using for health-related purposes, the final question asked the participants what new digital health technology they would like to see invented to suit their needs. Many of their responses referred to apps or devices that would work better to assist them with weight-loss or physical fitness efforts. They imagined technologies that would offer even more fine-grained detail than those currently available to them.

I think it'd be like an online diary where there's a monitor where I can enter what I've eaten for the day and it can break down the categories of the food types that I've eaten, whether it's impacted on my weight that day for the following day's weigh in and the amount of exercise and type that I've done and whether it's actually benefitting not just my general fitness but my overall health. Well, I think I'd be able to go back and look at a week at a time, a month at a time, or six months at a time and see marked progress and where things still need to be improved. Like a diagnostic thing, like I need to improve my iron levels, or I need to improve portion size, or I could add some type of exercise that would benefit more in my fitness and burning and building energy and maintaining muscle and bone. (Paula, aged 36)

I think it would be an exercise plan to keep you fit and healthy, maybe a menu for every day. A little app that puts up: this is what you should be eating today, how many calories that you should be consuming. That would be my ideal. I would perhaps download that if I went looking for it, I might look for an app like that. At this stage in my life, trying to keep my health would be more important to me. Which is something the Fitbit doesn't do at the moment, it does a lot of things, but it doesn't do that. (Sandra, aged 55)

Other participants also imagined software that could provide health and medical advice in a more personalised fashion.

Probably just something that tracks your blood pressure and maybe your weight or something like that. And maybe gives some suggestions, like how to have a healthier lifestyle. Just maybe the convenience of using it and not having to look up as much stuff yourself and maybe it might suggest some good things for me. (Jodie, aged 45)

Oh, just to have an app or something that would give a list of the likely bodily changes at different ages of life. So you know, at 73, what I could expect to be experiencing and then what would be beneficial, like exercise and diet things like that. Also, I guess an app where you could key in what your complaints are and you could narrow it down to what specific complaints you have and somewhere where you could enter your illnesses and receive advice about them. (Marie, aged 73)

Several women said that they would like to see software or devices that were more automated and easier to use. Frances, aged 63, suggested a device like wireless scales that could more easily record the calories of food she consumes: 'You could put your plate of food on the thing and it would go [makes noise], "This is your calorie value", etc. I'd probably be in that.' Susan, aged 56, imagined an app with voice recognition to help her enter her data: 'I could actually just talk into it as I was walking instead having to watch and type, which means I wouldn't need to worry about my glasses'. Louisa, aged 30, who is on many forms of medication for her chronic conditions, said she would like an app to manage her different prescriptions: 'It would be able to tell the chemist that your script had run out without me having to go in and actually hand in the script'.

Another common idea put forward was an imagined app that would combine many of the features the women find useful. This device might be able to track several aspects of their bodies and activities, thereby replacing the need to use several different apps.

I'd probably combine a few apps together or have the option to. I guess a lot of people would use fitness apps, and if it was just for me, it would probably combine fitness, the information that my Apple watch gets with the period one and maybe a sleeping app and combine it all into one app instead of having a bunch of different apps. And then I guess it would produce a report if anything did need to change, like my diet or sleeping pattern or general health, then it could produce a little report or something about that. I think it would help in making healthy habits and being a bit more consistent instead of just using an app for a short period of time. Being able to have something with a holistic approach that could help in a whole bunch of different areas instead of just one. (Ashleigh, aged 22)

I would probably have an app that would count my steps and would half plan my day, like an organiser. Like this is the workout you can do in this timeframe and if you take this walk at lunch, you'll hit this step count. And then maybe giving you recipes for what you should make for dinner so that your whole day is sort of planned around the health activities. It might be a bit intense for some people but that's something that would be really nice for me. (Emily, aged 25)

Some participants imagined an app that could combine the search features of Google with the functionality of an app to help them find information about symptoms and other health issues.

Maybe an app where you combined what you can do on Google like search symptoms and it pops up with all the possible things that could be wrong with you. Instead of having to do it through Google, just having it in an app. Then it could spit out treatments, like natural ones and then medical ones and then how long the symptoms will last and all that kind of stuff. (Amelia, aged 24)

You'd be able to access all the information, so probably what you can Google but put it into an app so you can get everything from that one app. Instead of having to Google it and then, you know, like, have to find something else – if you can press an app and it all comes up. (Diane, aged 56)

Alternatively, women suggested an app or platform that would bring together health data from a number of different sources so that they could all be in one place and could then be readily shared with healthcare providers.

Well, it would probably be an app that would do what the My Health Record tries to do (which no one's really using) but is also able to access the data from things like the Fitbit, and the scales and the other data that various devices are able to collect. I guess it would also be an app that would also help keep track of what medications you're taking and when you need to take them and when you might need to go and get a prescription. Probably an app that your doctor will be able to access to see what kind of information they need. It would be nice to be able to call a doctor and go, "Have a look at my app, I need the prescription for the pill". And they can look at it and make sure everything looks okay rather than going in and then them saying "Yes, everything's okay", the same as it's been for the last 12 years. That would be good, I think. (Maddie, aged 23)

I guess it would be, maybe something that was controlled by a university or government site, that was a little more specific – that yes, I guess I would have to put my details in, but being confident that that would be okay – and that was tailor made, and monitored and kept track of my health problems. A bit like a doctor's file, I guess, but something like that online, that I could actually look at myself, for which I could make suggestions of things to help or new information about a condition, like new research for a condition. (Sharon, aged 59)

Katrina, aged 38, would like to see an app that works well without constantly crashing and that did not constantly send out notifications. As she lives with a chronic health condition and monitors a number of features about her body, she would also like an app that collected personal health data and then readily exported the data to a platform where it could be easily viewed by herself or by healthcare professionals to whom she allowed access.

I think it definitely would be useful if that was somewhere where it could all sit together. And in a perfect world, if it was all the clinicians used it as well – if all your information was in one simple place and it was easy to navigate and wasn't just one big dump of information. And it was easily, you know, was easily categorised so you could find certain things.

Some women said that they wanted more direct contact with medical expertise using online technologies. For example, Laura, aged 27, said that she would like to see an online tool that could help her search online for health information that she could be sure was accurate and backed by medical expertise. She also imagined a resource that allowed her to ask questions of medically-trained professionals directly online.

Probably similar to, I don't know if it already exists, but probably a search engine which is just for medical purposes and it's been run by qualified health professionals, like doctors and stuff, so you know you could just punch in whatever your problem is and you know that you're getting an answer from a doctor. Or maybe even, I don't know if it exists as well, but even like an online chat where you can chat to a health professional, for free, I would say, where you can just directly through an online chat with a doctor or health professional. I would probably use that, because I use online chats for help for other things.

She would also like an app that could collate all of her health and medical information in one place, and one that was relevant to Australia rather than to the USA context.

The women in Focus Group 1, all of whom were caring for babies and were living with a mental health condition, had a discussion about the ideal health app for their lives. They decided that an app that sent them friendly, supportive reminders to care or take time for themselves and their own health and wellbeing is what was missing:

Participant: *It'd be nice if you had someone to just - if you could put an app on your phone that sends you really lovely friendly messages that were just sporadic reminders to drink water.*

Participant: *Just like...*

Participant: *Eat something healthy today.*

Participant: *That didn't make you feel bad about yourself.*

Participant: *Yeah.*

Participant: *That's a great app idea.*

Participant: *Just like a really nice message from your best friend but at random times on your phone.*

Participant: *Have you gone for a walk today?*

Participant: *Yeah.*

Participant: *Hey lovely, just make sure you have a cuppa and take some you time.*

Participant: *I genuinely need this in my life.*

Participant: *You know with the trackers for the sleeping and stuff, like, great job mum, now time for you to have some time to yourself.*

The middle-aged women in Focus Group 3 were in a different life-stage, and therefore had different suggestions for future digital health technologies. One woman said that she would like a device that would notify her when she needs to see a doctor, when she has some hidden illness that she wasn't aware of, or to remind her that she should have a vaccination or screening test: 'For us women in our age, beep beep, you need to have a mammogram, beep beep, you need to have a pap smear, beep beep, whatever'. The others agreed that this would be a good idea.

One woman who has migraines says she wishes there was an app or device that diagnosed these for her, as it took her a while to receive a medical diagnosis for the type she was experiencing, or helped her identify the triggers. Others mentioned apps that could automatically track blood pressure, vitamin D levels, iron, blood sugar, cholesterol levels or heart rate and warn the user if they were able to experience a health problem. They did note, however, that it was important not to get too obsessed with these kinds of monitoring, as it could ‘make you paranoid’, as one woman put it.

Health data privacy and security

As noted earlier, several women were concerned about how well their health and medical data would be protected by the My Health Record system, and these concerns were intense enough that they were unwilling to register. The final question in the interview or focus group asked the participants to comment more generally about whether they had any concerns about how their health data were treated across the digital health ecosystem.

For the most part, the women’s responses suggested a lack of interest or concern about the security of their personal data. For example, the women in Focus Group 1 said that they had rarely thought about these issues. They didn’t see how information about the bodily functions or habits of their babies would be of any interest or use to anyone else. As one woman put it: ‘With the baby tracker app, I’m just putting in things like when she’s slept and poed and I don’t think it would do any damage if someone knew that’. She went on to say that ‘I might feel a bit nervous putting up her photo’ but acknowledged that ‘I put photos and stuff on Facebook all the time’. The other women agreed that they found it difficult not to post photos of their babies on Facebook, because they are ‘so cute’ they want to share the images with their friends and family. They did go on to note that they are not happy about other people posting images of their babies on Facebook without receiving their permission. As one woman put it:

I’d be really pissed if someone posted a photo of my kid without asking. Because I post photos of my baby, and that’s my decision. Because I think because it’s like, well I like to think that I’ve got a pretty good control of who can see my posts. But if somebody else [did it] – I don’t know who can see your posts.

The women in Group 2 said that they weren’t worried about the privacy of health or development related information they put on online forums about their babies, as they were ‘closed groups’. They talked about the rules that many mothers’ Facebook groups had about joining: women had to prove they lived in the area for the Canberra Mums group and they didn’t allow fathers to join so that ‘delicate subjects’ could be discussed among women only. As they commented, while Facebook groups could be kept private to members only, the members themselves know each other’s identities as real names were used, and this could sometimes make people ‘self-conscious’ if women they knew from outside the group as well were on the Facebook group. Forums, however, were much more anonymous:

Participant: *If it’s on a forum, like just having user names and that’s it, so it’s even more anonymous than Facebook groups.*

Participant: *Some of the bigger ones, you can post anonymously so you just message them and say I want this anonymously posted and anonymous post sort of thing. Which I find good, because you don’t really want people to know who you are. People ask all sorts: like you’re going through a divorce or my husband’s violent and that sort of stuff. It’s all anonymous so no one actually knows who it is. I like that about those ones but I don’t feel I need to do that with my local Facebook group.*

The women in these groups were discussing their awareness of and thoughts about how other members of social media groups might access their personal details. They did not raise the issue of third parties exploiting their health data for commercial gain. This lack of interest or awareness in third-party use was evident among most of the other participants. Several women explained their lack of concern as being due to the belief that no-one would be interested in their health information and not recognising how it could be of use to any third parties.

I’m an open person, so I’m not too bothered by it, because I’m not putting deep, dark secrets about me in to these apps. It’s more general knowledge about me. (Ashleigh, aged 22)

I couldn't care less. I'm pretty boring. I don't think anyone's going to want to find out much about me. (Marilyn, aged 67)

It was difficult for most participants to identify what might happen to their personal information traces when they went online or used apps. As Pearl, aged 72, put it:

Once you get used to these technologies you forget that somebody is watching you. I don't worry about it too much; I think it's a sign of the times. There's lots of apps and lots of things we do now where someone is watching you one way or another, you know cookies on the computer and all of that. And I don't think you can avoid it really. Who do you think might be accessing or using the information? Oh – Big Brother? No I don't know. Probably you think at times the government would be in the back there keeping tabs on you, maybe Centrelink.

Many women said that they had begun to notice how their personal data may be used by advertisers: for example, following an online search for a health issue.

I mean, you see cookies, you make an enquiry about a holiday or travel or something and immediately cookies pop up in that very place so that you know that someone is monitoring what you're doing. (Margaret, aged 73)

It amazes me sometimes that I might go onto a health site and then I maybe on something totally unrelated and it'll pop up or come up, and I think, "How did you get that? Because I didn't give you any information whatsoever!". But I am aware of it. (Sandra, aged 55)

Some women thought that there was now so much of their health data available online that there was no point being concerned about it. One example is Anna, aged 30:

I'm not really worried, because the amount of stuff that I have on the internet already, I'm out there. Yeah and that sort of stuff, I find is – it's general enough that it wouldn't make a difference if it's out there. The only thing that might be different would be GPS tracking on your running device. But then if you don't sign up with your regular user name, if you had a generic one, you can get around that. I'm not super worried about privacy.

Anna went on to observe that she never bothers reading through privacy agreements on apps and other software, and that she had simply decided to invest her trust in the companies she uses:

Privacy agreements, I don't really care about because it's all pretty standard anyway and if they do something dodgy, then it's my fault anyway. Yeah, I've just got to trust that they don't. For me it's just blind faith.

Other women simply did not think much about their data, despite being aware that there were potential security risks, while others thought that their health information was well protected.

I don't think about who uses my health data, but I suppose I should because there are hackers and scammers around, but I don't really worry about it. (Audrey, aged 69)

I'm not really worried. Most things are relatively secure and have safety things in place. (Lynne, aged 55)

Jessica, aged 24, says that she doesn't think about privacy issues in relation to the personal data she is uploading to her nutrition app.

I don't read terms and conditions. It's never crossed my mind the thought that they could be passing on information about what I eat to anyone. Not that I would particularly care.

She went on to explain that because the app is marketed as a tool for people to improve their health, the tracking and surveillance aspects of the app tend to be ignored by users such as herself. She also commented that the surveillance aspects of the app are not very obvious to users.

Because I'm not thinking about the idea of surveillance or privacy. Because it's so, like, marketed to the realm of health and it's so marketed to, like, you. So it's, like, this is my app, for me to improve myself and if someone had information on my age and my body weight and how many calories I'm eating each day, I've never really thought about it before.

Erica, aged 55, demonstrated an ambivalent attitude to health data privacy. She can see both the positive side of being tracked by others and the negative side.

On the one hand, there is that sort of concern, about people you can be tracked, there's a satellite tracking you and so on and so forth ... It's like with the security cameras on, tracking you around the place. I don't have any major concern about it. If I was out, going around the lake and someone attacked me, then maybe people will be able to find me quicker than if I didn't have any of this stuff ... I'm a bit of a fatalist about it all really, like I say I think we've probably tipped over in to a point where there's not a lot we can do about it. I mean the minute you buy a smartphone, you start using it, then you're stuffed. I just try and follow the common-sense rules about things. But I suppose I like to live my life in blissful ignorance about it all.

Other people commented that they did not use personal details such as their names when interacting online and therefore their personal details could not be linked back to them.

No, I don't think about where that information goes because I'm not actually putting in any of my details, I'm simply researching. I'm just looking online and gathering information I'm not on a forum or a blog or something where I'm giving any of my details or information. (Sharon, aged 59)

Several women explained that they were concerned about marketing companies using their information for advertising but felt that they could do little about it if they wanted to continue to use online services like Google because of the convenience they offer.

I think it's quite intrusive. I haven't given the advertisers permission to use that information. It concerns me how much they need to know about you. I still use it, I still go on Google even though I know they are watching every word I type. But I think it is just about time as well – I don't have time to go to the library for the answer. (Houda, aged 45)

Well I do worry, I often think about that, because I do know that if you're researching something on Google and you've got all these things popping up, I know as a result of going to these websites, not even related to health I guess, but to other things, you can see these things coming through because you've looked up something else ... It does bother me a lot but I do know that is the internet, what can you do? (Bernadette, aged 53)

Although many participants were aware that their personal health data could be exploited by third parties other than advertisers and the big tech companies, their knowledge was limited concerning exactly who these actors would be. For example, Margaret, aged 73, commented that: 'Yes data collection is a problem. To be honest, I don't know who is monitoring those things and getting the information'. A small number mentioned the implications of health insurers gaining access to people's personal health information. Sandra (aged 55) suggested pharmaceutical companies 'may be looking what is relevant nowadays. For example, anxiety – mental health is pretty big at the moment, they could be looking at that, you know, drug companies'.

Most of the women had not yet been directly affected by third-party use of their health data and therefore were not placed in a position where they needed to consider privacy and security issues. A number of women made reference to possibility of 'hackers' or 'scammers' who might access and use their health data, but they were not sure exactly what these actors might do with the information.

My feeling is that once your information is entered somewhere, it's going to be fairly easily accessed by a broad spectrum of organisations. Well worst-case scenario, scamming type things, and probably I don't want annoying calls with organisations following up. I basically want to do my looking up on my terms, I don't want to be bombarded down the track. (Suzanne, aged 62)

Probably most annoying would be advertisers and marketing but it could be anything, because once you link your Facebook profile to it, that's your name, your age, any family members you've got listed, your phone number if you've got it connected, your email is linked to your Facebook. So you could be open to a lot of scams. That sometimes worries me. (Emily, aged 25)

When Frances, aged 63, was asked if she was concerned about a company getting access to her Fitbit data, she said that she doesn't see this as a problem: 'Well it's a matter of what sort of information you give it. I mean, frankly I don't care who knows how many steps I've managed or haven't managed'. Frances went on to note that even though she is legally trained, she doesn't read the privacy and terms of conditions policies of devices and apps like Fitbit. She stressed again that she doesn't think of the information that Fitbit collects about her as sensitive and therefore isn't worried about any third party viewing it. Frances did recognise, however, that she was in a privileged position and that other people's medical details could be potentially used against them by actors such as health or life insurance companies.

But again, that reflects my reasonable confidence about my health. If I were unsure about it or in a situation where I did depend on a life insurance policy rather than a generous pension – put it that way – then I might feel more strongly about it, yeah.

Sally, aged 41, could acknowledge the benefits of people's medical data being collected for research and planning, as long as it is anonymised. But she can also envisage a situation where her own information about her pain condition could be used against her.

On the one hand, I have advertised a bit in the world that I have chronic pain and whatever. But I also know that could bite me for further job opportunities or stuff in the future. I don't want someone to have access to that kind of information unless I consent to it.

Sally later went on to say that she is not concerned about who might collect and view other data about her:

But I mean, if there is a Big Brother running the universe that I don't know about, then I probably don't know what – how they're collecting the data on me and I don't really care. The government in this age don't have enough resources to be watching us that closely and I don't think I'm doing anything particular exciting to care. If they want to watch me go to the grocery shop, sure go for it. I've got my rewards card, someone knows what I'm buying anyway. I can see that other people have a lot of fear about it and that's legitimate, because people do use data that you don't understand how they're going to do it, especially to sell you stuff. People don't like that and that's fine, it doesn't bother me.

Sally has not really considered to any great extent the health privacy implications of data about her young son's health that might be collected online. When asked about it, however, she did begin to realise some potential problems, particularly if he developed an illness that was stigmatised. In reflecting on these issues, Sally began to consider in broad terms what data privacy would involve, and drew attention to the contextual nature of privacy:

If he's got some terrible communicable disease, or he's HIV positive or something like that, yeah, then I would have a huge concern about privacy. Yeah, so I don't know whether – at the moment privacy is like yes or no kind of thing. It's not like we've got a scale, we're going to be really private about this, not so private about that. We don't care about that. Yeah, I think everybody else has a different scale of what privacy they want around different things.

A small number of participants said that they did take steps to protect their privacy, including exerting caution about revealing information about themselves in online forums or social media.

I tend to not put in personal details and anything I can avoid purely because I don't want it going in the wrong hands. So I would only ever put in general information not specific because yes I agree your personal records are something you don't want everybody knowing about. (Margaret, aged 73)

Lara, aged 33, who valued the anonymity of online forums, said that she made sure not to use her real name when engaging online.

Oh yeah, I definitely think about privacy, but I try when I do go on to these forums I don't use my real name or anything like that. So I'll use a pseudonym or something that can't really be tracked to me. I wouldn't want it to be used against me in case of health insurance or something like that ... I might hesitate to say too much about myself or my family. But if I do need to use examples, I'll just use like generalising rather than specifics. Or if I do specifics, I won't say this is real life or anything, I'll just say that it's an example.

Lara went on to note that even though she engaged regularly on Facebook pages for parents of children with a disability, she took steps to protect her daughter's identity.

I don't really post, like the Facebook group for my daughter's disability, I don't really post on there about her. Other people will post pictures of their children and write lots of things, but I kind of use it more for information gathering. Occasionally I will comment generically but I don't kind of publicise our address or anything like that. More just because like – it is a private group I don't really want to be contacted by people in the group. So yeah, I do think about it.

Hannah, aged 34, was beginning to consider the privacy implications of her husband using Strava in terms of whether criminals might be able to track his location. She has also been thinking about the personal data that are entered into health apps as well as the data implications of My Health Record. For her, these were issues that may need to be considered in the future, once they become more relevant to her.

Back to the privacy thing – sometimes I do think about my husband and Strava that his movements are known to anyone who wants to look like they can see he goes cycling on these days of the week and this is what time he goes. And I don't worry about it too much, but like, if someone wanted to come rob our house or whatever it's just if anyone was watching, it would be all there laid out. But it's not a big enough concern that I want him to stop using it or anything like that. But I do think it would be, yeah, I guess privacy around the health apps and that kind of and then taking that through to the government medical portal and having that information protected so that people couldn't see about your conditions and that kind of thing. Because I know there are lots of cases for things like life insurance. And like, I'm not at the stage of life when I need to worry about that, but down the track that will be important, like I would be interested before I signed up to know how my information would be used.

Katrina, aged 38, said that she did take the trouble to read the privacy policies of apps she is considering downloading to her phone. She looks to see whether the policy makes mention of whether her personal information will be de-identified or passed on to third parties.

Most of the time if I know that it's going to be de-identified so if it can't be attributed back to me – like if my answers or things that I've said can be used but cannot be attributed back to me, then I'm totally fine with that ... But if it was something personal about my specific circumstances, then I would care.

Chelsea, aged 28, is one of the few participants who expressed high levels of concern about her health data privacy and security. She works in genetic research, and is aware of the possible implications of collecting people's genetic data, even if they have consented as part of a research study. Chelsea reported that she deliberately uses an early model iPhone and has disabled GPS tracking and Bluetooth on it because of data privacy reasons. Chelsea said that 'it is the general principle of the thing' that concerns her about personal data privacy and security.

I'm concerned with the erosion of value of privacy in modern life, in almost every single sphere. It's impossible to really avoid completely without dropping out of society and I'm not a 'cabin in the woods' kind of person. But I don't want to be broadcasting my location. Like anything about me, unless it's something which I've made the step to actually choose to do and provide that information, it's more the principle of it than anything else.

Chelsea went on to make a distinction between the public use of her health data to which she had consented, and the use by third parties of her data for commercial purposes without her consent.

If there was a public database that looked at heart rate based on age or occupation or whatever, and they said wear this Fitbit or whatever to contribute to a public database, your data will be de-anonymised and other people can access the data: that's completely fine. Because I've consented, I know what's going on. But the idea of wearing assorted sense wear for no reason, for myself or for others, and then having that information taken and potentially most likely sold for advertising purposes these days, I don't really like that.

Chelsea doesn't distinguish between commercial and government entities in the responses she has to sharing her personal data. She noted that the Australian government's failure to conduct the last national census properly online is demonstration that 'they don't know what they're doing really', and they are not to be trusted. 'I know they're well-meaning, but a lot of them, their sense of data security is kind of shit.'

Lien, aged 21, is also concerned about the privacy of her personal data, particularly as she uses apps and social media groups to discuss very private topics such as sexual and reproductive health:

Sometimes I feel it helpful. I like the idea that I'm getting to know my body because it's mysterious and I don't know about it. I love the idea, but sometimes I'm worried about my privacy. How I move, where I go, and how my sleep pattern is, because I'm - because the sleeping track thing is a device. It's actually a Christmas present from my friend, and it was feeling like, is she going to know how I might sleep? Will the data be sent to her? ... Just about the privacy part, my location and kind of thing. Would they know - and how long my thing, my data, is going to be stored, and how long they're going to keep it. Is anyone going to know it?

DISCUSSION

The findings from the Australian Women and Digital Health Project revealed new insights into how Australian women across a range of ages, geographical locations and education levels are using the spectrum of digital technologies available to manage and support their health and wellbeing. Older digital tools and sources such as search engines, websites and online discussion forums are often neglected in contemporary discussions of the potential of digital health, while newer digital media such as apps, wearable devices and social media receive high levels of attention. An important finding is that these older digital media remain very highly-used and valued among the participants. Regardless of their sociodemographic characteristics, our participants were avid users of online tools and resources such as search engines and websites to find health and medical information. They referred to valuing the affordances of instant and up-to-date information, the opportunity to search for information privately or anonymously and the peer support that they could find online. Those women who used apps and wearable devices appreciated the opportunity to automatically monitor their bodies, engender motivation and work towards health and fitness goals.

The participants were actively working with digital technologies to source, assess and apply health information and advice to their circumstances. They embraced the ideal of responsible citizenship promulgated by the 'digitally engaged patient' discourse (Lupton 2013a). It was notable that many participants reported frequently searching for information on behalf of their male partners as well as other family members. No women mentioned that any family member reciprocated this information sourcing on their behalf. Women have traditionally adopted this gendered role, taking responsibility for protecting and promoting the health of partners, children and elderly parents (Lupton 2013b). These findings show that they are now using digital technologies to perform this type of 'reproductive citizenship' (Lupton 2014; 2016a) and family caring role.

The participants' accounts revealed that a range of capacities were generated with and through women's engagement with digital health technologies. These included the capacity to seek and generate information and create a better sense of knowledge and expertise about bodies, illness and healthcare, including the women's own bodies and health, that of their families and friends, and that of their often-anonymous online social networks. Affective forces such as motivation, reassurance, comfort, achievement, connection, empowerment, trust, competition, friendship, companionship, feeling in control, feeling knowledgeable, a sense of community and belonging were recounted in their accounts of digital health use.

Women described a sense of empowerment from being able to readily access health information online and decide whether or not their concerns about their bodies or the health of family members were warranted, could be dealt with using lay remedies or required a medical appointment. The participants referred time and again to the capacities of agency and control that using digital health technologies afforded them, including feeling as if they were able to better manage their own health, and in many cases, that of their family members. When the technologies failed to work as expected, these capacities were not realised. Women responded with feelings of frustration, disappointment and annoyance, leading them to become disenchanted with the possibilities of the digital technologies they had tried.

Education levels or geographical location did not appear to play an important role in women's use of digital health. However, age, life stage and whether a participant was living with a chronic health condition or caring for a child or other family member with such a condition were influential. Reflecting general trends among Australians (Yellow 2018), the use of social media groups, apps and wearable devices was more common among young and middle-aged women compared with those aged 65 and over. Women with a chronic health condition or caring for a family member with such a condition, as well as those experiencing pregnancy or caring for young children, were among the most avid users of health websites, social media groups and online forums, seeking peer support and alternative information sources to those offered by doctors as well as orthodox medical advice. However, these women could often be frustrated by the design of apps and wearable devices that did not recognise or cater for their needs in their current life stage or state of health. They did not want to be nudged towards feeling guilty or ashamed by notifications from apps or wearable devices, and felt resentful when this occurred. In these cases, the technological affordances did not align well with their bodily affordances and the demands of caring responsibilities.

Women's participation in digital health, as this suggests, involved relational connections that involved a set of human actors – family members, friends, healthcare professionals and often anonymous online contacts – entangling with digital technologies and digital data. A key element in these connections was the strength of trust that women felt

they could place in other people to help them with health-related difficulties. In this context, digital technologies mediated these relationships mostly for the better, working to strengthen, enhance and expand them well beyond women's immediate geographical location. However, it was also evident from the women's accounts that face-to-face encounters remained integral to their lay health knowledges and practices, including friends and family as well as practitioners. Whether digitally mediated or in-person, women highly valued knowledge that was localised and personalised, directly relevant to their circumstances. Sometimes in-person encounters (chats at the school gate, participation in face-to-face support groups, visits to doctors) offered this type of knowledge far better than mediated communication. Here again, women often acted as the disseminators of health knowledge to friends and family.

Trust was an important affective force emerging in women's accounts of how they evaluated online sources of information, what they did with this information, and how they interacted with their medical practitioners. The participants positioned their digital health activities as supplementing rather than replacing expert medical advice. As this suggests, online resources have increased the capacity of lay people to access both medical and lay expertise. Lay expertise was valued for its personalised insights into the everyday worlds of living with a condition and information about which treatments can work best, while medical expertise was valued for its authority, clinical experience and facilitating access to other resources such as medical testing, drug prescriptions and specialists. Medical experts tended to be positioned as being able to confirm and validate a self-diagnosis or self-sourced therapy, or alternatively, to allay fears that symptoms were serious. Rather than online health resources competing with expert health professionals, therefore, they were used in a complementary manner by the participants: often in ways that reduced their recourse to face-to-face medical services.

In a sociocultural context in which women's bodies are typically represented as leaky, volatile and unpredictable, requiring better disciplining and self-management (Grosz 1994; Shildrick 1997; Longhurst 2000), digital technologies such as self-tracking apps and wearable devices offer women the opportunity to overcome the unruliness of their bodies. In some cases, however, as the women's accounts demonstrated, their bodies and lives did not intra-act well with the technologies. Thus, for example, women's embodied responsibilities for and relational connections to their young children, part of performing 'good motherhood' (Lupton 2013b), clashed with the demands of the technologies. A series of difficulties relating to their app and device use were recounted by the women, surfacing the ways in which agential capacities could be closed off when technological affordances did not mesh well with embodied affordances or the demands of performing caring. The life stage which women were currently experiencing and whether they were living with demanding caring responsibilities, attempting to ward off the potential loss of fitness or ill-health that growing older could engender, or dealing with a chronic health condition, were key biographical and social contextual elements that emerged in the women's accounts of their app and device use or non-use.

People's health and medical data generated from their online interactions and app and wearable device use can be very revealing of intimate details about them, some of which may render them vulnerable to discrimination, exclusion from opportunities, financial penalties or stigmatisation. These details have high value for third parties, including internet and app companies that can sell people's health data to advertisers (Huckvale et al. 2015; Wicks and Chiauzzi 2015; Monteith and Glenn 2016), data mining, brokering and profiling companies (Libert 2014), health and life insurance companies who can use some of this information to calculate premiums or to offer rewards to customers for reducing their health risks (Olson 2014), health and medical researchers seeking to make use of big datasets, and government agencies making decisions about healthcare policy and provision. These data can also be used illegally by cybercriminals engaging in identify theft, including make fraudulent health insurance claims, claiming fees from organisations to release hacked medical datasets using ransomware and seeking to blackmail people on the basis of sensitive personal data (Ablon et al. 2015; Athinaiou 2017). In Australia, medical data is the most breached of any other type of personal information (McLean 2018).

My previous research on how Australian women are using apps and the internet for pregnancy and parenting identified little evidence of concern about personal health information privacy and security among the participants in a survey (Lupton and Pedersen 2016) and focus groups (Lupton 2016c; 2017b). Similar responses were evident among participants in this project. Most of the women said that they did not think much about who might access their personal health and medical data and nor did they express high levels of concern about their personal information privacy and security. They explained that this was due to several factors: a belief that their data were well-protected or that no-one would be interested in their health details, resignation to the fact that there was already a lot of their

health information online, not having thought much about the issue, not realising that their information could be accessed and used by third parties or simply investing their trust in the companies that they used. Very few bothered reading privacy policies or terms and conditions for the software they used. A minority of women had established approaches for protecting their privacy or that of their young children, such as participating in closed Facebook pages or never using their real names or divulging intimate details in online forums. It was difficult for most participants to identify what might happen to their personal information when they went online or used apps. The women were aware of how advertisers used such data as their online searches to target advertising to them, and for the most part accepted this as a condition of using internet companies' or app services. While some participants could imagine ways in which people might be adversely affected by third-party use of their health data, these privacy and security issues had not yet directly affected them or their family members.

When the participants described the types of digital health technologies they would like to see invented to best suit their needs, convenience and clarity of information were central affordances. They wanted apps or other software that would do everything they needed: generate, store and process their health data, answer queries. The women imagined devices or software that could readily respond to their need for information and clearly outline options or solutions. They described software that would bring together information from disparate sources, including their own health data, and present it in one place. These responses demonstrate the importance to women of being able to meaningfully interact with health and medical information and their personal health data in a context in which this information is constantly changing and expanding.

These findings further serve to highlight the tensions that can exist between the different demands that women in wealthy countries like Australia face when attempting to conform to idealised and normative femininities. The women's successful enactments of health apps and wearables that worked toward achieving the healthy, active, controlled body imagined by these technologies were disrupted or challenged by the demands of pregnancy, breastfeeding, chronic pain or disability or achieving the ideal of the caring mother who devotes most of her health-promoting efforts to her children. Standard health and fitness apps and wearables have not been designed with these bodily states and affordances in mind. It is not surprising, therefore, that women imagined novel health technologies that would better cater for the diversity of their embodiment and demands of their everyday lives.

A limitation of the project is that while it included quite a diverse range of Australian women, there was an over-representation of women with a university education, those living in a metropolitan area and those from Anglo-Celtic and English-speaking backgrounds. Further research should direct more attention to women who are members of more socio-demographically disadvantaged groups. Their experiences of digital health may be different, as their access to both digital technologies and health services tend to be more limited than women who are more advantaged (Baum et al. 2014). In-depth studies focusing specifically on Australian men's uses of digital health, another neglected area of research, would also draw further attention to the gendered nature of the enactment of digital health technologies.



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