

Online resources and apps to aid self-diagnosis and help seeking in the perinatal period: a descriptive survey of women's experiences

Nicola Mackintosh , Shona Agarwal , Kirsty Adcock ,
Natalie Armstrong , Annette Briley , Molly Patterson ,
Jane Sandall , Qian (Sarah) Gong

PII: S0266-6138(20)30175-3
DOI: <https://doi.org/10.1016/j.midw.2020.102803>
Reference: YMIDW 102803



To appear in: *Midwifery*

Received date: 31 March 2020
Revised date: 7 July 2020
Accepted date: 18 July 2020

Please cite this article as: Nicola Mackintosh , Shona Agarwal , Kirsty Adcock , Natalie Armstrong , Annette Briley , Molly Patterson , Jane Sandall , Qian (Sarah) Gong , Online resources and apps to aid self-diagnosis and help seeking in the perinatal period: a descriptive survey of women's experiences, *Midwifery* (2020), doi: <https://doi.org/10.1016/j.midw.2020.102803>

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Online resources and apps to aid self-diagnosis and help seeking in the perinatal period: a descriptive survey of women's experiences

ABSTRACT

Objective: Assess the role of online resources and apps for women's help seeking and staff's response to concerns in the perinatal period.

Design: Online survey. Descriptive analysis of women's use and experiences of digital resources for self-diagnosis and help seeking, drawing on numerical and free-text responses.

Setting: Two tertiary referral centres and one district general hospital in two UK geographic locations.

Participants: 632 postnatal women, surveyed over a 4 month period

Measurements: Women's access to digital devices; frequency and type of health concerns experienced after 22 weeks' gestation; variability in use and experiences of websites/apps; perceptions of staff's response to concerns after help-seeking.

Findings: 1254 women were approached over a 4-month period; 632 participated (response rate: 50%). Women reported a 'mix and match' blended use of digital resources to both learn about, and self-diagnose/self-triage for potential complications in pregnancy as an adjunct to care provided by maternity staff. Over half the participants experienced concerns about themselves or their baby after 22 weeks. The top concern was fetal movements, reported by 62%. Women used 91 different digital resources to help with understanding and decision-making, in addition to seeking support from family, friends and healthcare professionals. Enabling features of staff responses were identified from free-text responses (n=292) by women who sought professional help regarding their health concerns, and influencing factors at clinical, organisational and digital level.

Key conclusions and implications for practice: Online information retrieval and digital self-monitoring is increasingly integral to women's self-care during pregnancy and offers opportunities to

support escalation of care and shared decision-making. Further work should assess optimal inclusion of this 'digital work' into clinical consultations.

Keywords: health concerns, self-diagnosis, online resources, perinatal care, eHealth

Journal Pre-proof

INTRODUCTION

Perinatal morbidity and mortality are global public health issues. Stillbirth remains a major health burden, with variation in rates across, and large equity gaps within, high-income countries (Flenady et al., 2016). Women's experiences during pregnancy and birth, and postnatally, have profound psychological, physical, social and economic consequences for parental and child health immediately after birth, but also for the long-term health of mothers, their children, and beyond (Heazell et al., 2016; Nuzum et al., 2018).

Increasingly, global attention is directed at risk management and digital self-care before, during and after pregnancy to reduce perinatal morbidity and mortality (UN, 2014; WHO, 2016). Traditionally, health education aimed at women in pregnancy includes face-to-face education, pamphlets, audio-visual training and mass media campaigns. Increasingly, the important role of online pregnancy resources is recognised (Grimes et al., 2014; Sayakhot & Carolan-Olah, 2016; Slomian et al., 2017). Charities and public health education programmes routinely use digital platforms to inform women about 'red flags', early warning signs of perinatal complications, and appropriate help-seeking (e.g. Tommy's charity, 2017).

Studies have shown that searching for online resources about pregnancy complications can be quick and easy, and can provide legitimacy for women unsure of the significance of their symptoms to seek professional help (Prescott & Mackie, 2017). But concerns have been raised about the quality of the information provided (Farrant & Heazell, 2016), women's competency to assess the accuracy of information retrieved, and the accessibility and readability of numerous online resources (Berland et al., 2001; Eysenbach et al., 2002). A woman's level of health literacy influences her ability to source information and subsequent health knowledge and behaviour (Shieh et al., 2009). While digital resources can enable women to self-diagnose, seek help and speak up about safety concerns (Mackintosh et al., 2017), online information and apps may arouse feelings of heightened anxiety, awareness of risk, self-responsibility and blame (Lupton, 2013; Thomas & Lupton, 2015).

Research in this area has tended to focus on women's pregnancy and post-birth information needs rather than their specific needs related to self-diagnosis and help seeking. There is a lack of understanding about the prevalence and variability of this form of digital use. There is also a dearth of research exploring how online resources inform and supplement or work *alongside* professional services. Digital resources largely operate within a separate 'social space' to clinical consultations. This paper reports a survey study addressing this knowledge gap. Our objectives were to assess: *who* uses digital resources to aid self-diagnosis and help seeking; *for which* potentially serious symptoms and clinical conditions; *which* resources are used, and; *what* role they play in women's decisions about whether to seek help (or not).

METHODS

Study design

A descriptive design was used to describe women's use and experiences of digital resources for self-diagnosis and help-seeking, both numerically and via text responses. The survey was part of a mixed-methods study to address the gap in understanding how digital resources 'work' alongside the provision of professional maternity services. The descriptive survey was followed by interviews with women and staff (midwives and obstetricians), and a social semiotic analysis of specific digital resources (not reported here).

Setting

A maximum variation sampling approach was used, purposively selecting three [UK](#) sites (two large urban and one rural district general hospital), across 2 different geographic locations (London and the East Midlands) to act as information-rich cases and to maximize the diversity relevant to the research topic. Use of online resources is known to differ by age and socio-economic group, and is linked to network connectivity, as well as social and digital skills (Ofcom, 2019; ONS, 2019; van Dijk, 2013). These sites were selected to enable exploration of theoretical propositions related to differences in digital access and use, as well as linked characteristics such as urban/rural, language

competency, education and employment statuses. Site 1 delivers around 6,500 babies each year; services include an obstetric unit, a midwife-led unit and a private maternity suite. Site 2 delivers around 11,000 babies each year; services include two obstetric units and three midwife led units (including alongside and free-standing units). Site 3 delivers 3,700 babies each year; services include an obstetric unit. Inclusion of two tertiary referral centres ensured access to a wide range of women, including those with comorbidities and complex medical problems. All three sites served areas with varying levels of deprivation and diverse populations of women from different socio-economic, cultural and ethnic backgrounds. We were not looking for statistical significance, but instead aimed to identify common characteristics of those women, who, for example, experience difficulties accessing and using online resources. [Table S2 provides supplementary contextual details including staff reports of information resources women were routinely signposted to at each of the three sites.](#)

Participants

Posters displaying project information were displayed in clinical areas frequented by pregnant and newly-delivered women. Those over 16 years of age were recruited prior to discharge on the postnatal wards at the three sites from 1st May 2019 until the pre-defined sample size was reached by 31st August 2019 (details below). Prior to recruitment, research midwives/nurses/support officers screened the women, to assess cases of safeguarding issues or where additional support was needed for women who had experienced adverse outcomes. Potential participants received a patient information leaflet explaining the study and what participation would entail. Those willing to take part were asked to complete a consent form, and then provided with the online survey to complete. Assistance was provided by research staff with the administration of the survey to enable inclusion of women with limited digital literacy or understanding of written English. However, sampling was to some extent opportunistic and dependant on availability of research staff, and largely occurred during office hours.

Survey design and administration

We designed the survey to build on previous instruments seeking to assess women's use of online resources and apps in pregnancy (Grimes et al., 2014; Lupton & Pedersen, 2016; Slomian et al., 2017), with reference to literature accounting for graduations in digital inclusion (Livingstone & Helsper, 2007; van Dijk, 2013; Warschauer, 2004). The survey was developed by the research team, in conjunction with our advisory group, and took between 10 and 30 minutes to complete. The survey was piloted via parent networks accessed through SANDS and the Good Things Foundation to enable face validity. In response to feedback from the pilot, we moved the demographic questions to the end of the survey and simplified the wording in two of the questions.

We used multiple methods for our survey design and administration, to enable participation for those with English as a second language, or lower digital and health literacy skills. Our principal means of administration was via iPads incorporating visuals, alongside a paper option. We selected GoSurvey (www.gosurvey.in) because of its offline capabilities given variability of Wi-Fi access across the 3 sites. Posters, project information and the survey were translated into the five languages most commonly used across the three sites (Gujarati, Hindi, Polish, Spanish and French). Support to help with survey completion was accessed where possible via research staff bilingual in Gujarati, Punjabi or Polish.

Data collection

The survey included closed, multiple choice and open questions with free-text response, and a filtering process for specific questions. Section 1 consisted of nine questions about internet use and routine access to information and support, and use of websites and apps during pregnancy. In section 2 women were asked if they experienced health concerns during pregnancy. Ten follow-up questions asked about the nature of these concerns, women's use of online resources and apps to aid help-seeking, actions taken as a result, and response received from staff. Three questions were asked for free-text responses: 'Please tell us your top three websites and/or apps you used the

most'; 'What actions, if any, did you take as a result of accessing these resources?' and 'How did you feel your concerns were responded to by the midwife/or other medical professional?'. The last section asked women for demographic details.

Sample size

We estimated discharge rates across the five postnatal wards and midwife-led units across the three Trusts at an average of 950 per month, which with a response rate of 40% (based on studies employing similar methods of recruitment (Grimes et al., 2014; Larsson, 2009)) would generate a sufficient sample to describe women's common/typical experiences. Our minimum target was 400 and we extended our recruitment by a month to ensure we reached this.

Data Analysis

Data were descriptively analysed using frequencies and percentages using the Go-Survey analytics software and SPSS. Analysis focused on identifying characteristics of the population surveyed to make theoretical inferences (theoretically valid connections between events and phenomena) rather than empirical generalisations. Responses to open-ended questions were analysed using content analysis (Garcia et al., 2004; O'Cathain & Thomas, 2004).

FINDINGS

Characteristics of women who participated

1254 women were approached to take part in the survey; 658 women participated. However, only 632 surveys successfully uploaded (due to connectivity problems). The response rate (based on usable surveys) was 50% (632/1254). Recruitment varied from 41% to 78% across sites. We collected postcode data from our respondents (n=609; 23 missing or unusable) which enabled us to measure how our participants ranked according to an index of multiple deprivation (IMD). The IMD provides a measure of relative deprivation information on material living conditions in an area or neighbourhood relative to the rest of the UK. ~~Postcode data from our respondents (n=609; 23~~

~~missing or unusable~~ Postcode data showed a spread of index of multiple deprivation (IMD) scores across the deciles with 7% (40/609) of women in decile 1 (most deprived), 6% (35/609) in 10 (least deprived), with the largest number in 3 (19%; 115/609) (Ministry of Housing, 2019). Table 1 presents characteristics of respondents. The majority of women were aged 30-39 years (53%), from a white ethnic group (61%), were married or in a civil partnership (57%). Just under half were employed full-time (49%) and 29% had an undergraduate degree (associate or bachelors). Of the 596 who declined to participate, the most frequent reason was lack of interest (48% n=285). Despite having multiple language versions of the survey, 13% (n=78) cited language barriers for declining participation, highlighting variable availability of multilingual research staff to aid recruitment.

Table 1: Demographics of respondents

Demographic	N=632
Age (years)	N=632 n (%)
< 20	10 (1.6)
20-29	247 (39.1)
30-39	333 (52.7)
≥ 40	42 (6.6)
Ethnic group	N=632
White	383 (60.6)
Mixed/Multiple ethnic groups	19 (3)
Asian/Asian British	71 (11.2)
Black/African/Caribbean/Black British	61 (9.7)
Other ethnic group	85 (13.4)
Prefer not to say	8 (1.3)
Missing	5 (0.8)
Employment	N=632
Full-time (≥ 35 hours a week)	312 (49.4)
Part-time (≤35 hours a week)	123 (19.5)
Self-employed	42 (6.6)
Unemployed looking for work	33 (5.2)
Housewife	69 (10.9)
Student	19 (3.0)
Unable to work	23 (3.6)
Other	11 (1.7)
English as first language	N=632
Yes	506 (80.1)
No	126 (19.9)
Language support given to complete survey	N=126
Yes	23 (18.23)
No	103 (81.7)
Highest education level	N=632

Primary school	7 (1.1)
Grammar/secondary/high school	96 (15.2)
Technical college/diploma	133 (21)
Apprenticeships/vocational training	47 (7.4)
Undergraduate degree (associate or bachelors)	185 (29.3)
Postgraduate degree	137 (21.7)
Other	24 (3.8)
Missing	3 (0.5)
Previous live births prior to this pregnancy	<u>N=632</u>
No	348 (55.1)
Yes, 1	195 (30.9)
Yes, 2	63 (10)
Yes, 3 or more	26 (4.1)
Previous miscarriages, stillbirths, neonatal deaths, terminations	<u>N=632</u>
No	416 (65.8)
Yes, 1	135 (21.3)
Yes, 2	55 (8.7)
Yes, 3 or more	26 (4.1)
<i><u>Percentages may not equal 100 due to rounding</u></i>	

Although uptake of translational materials was minimal (only 2 surveys were not completed in English), for 126 (20%) of women, English was not their first language, and 23 (18%) received language support to complete the survey. The majority of women (55%) were nulliparous prior to this pregnancy and (34%) had experienced pregnancy loss (miscarriages, stillbirths, neonatal deaths or terminations).

Women reported using a number of digital devices (e.g. desktop, laptop, iPad), the most common of which was the Smartphone (used by 97%). Three women (0.5%) reported no access to digital devices. Of those with access to digital devices, (95%) used the internet daily. One reported never having used the internet, while seven (1%) classed themselves as occasional users (less than once a week), and 25 (4%) as weekly users (one or more times a week). Reasons such as lack of time, lack of internet access, visual impairment, worries about safety, and lack of interest were cited for non/occasional internet use. Filter questions in the survey enabled the three respondents without digital devices and the non-user to bypass follow-up questions on digital use, but still to answer questions about health concerns, actions taken and staff response. Subsequent responses regarding digital use relate to the remainder sample, classed as digitally active (628).

Routine access to information and support during pregnancy

The majority (88%) of women reported that midwives (face-to-face or via telephone) helped them to feel informed about normal pregnancy related changes and signs of a complication, with 51% and 48% of respondents acknowledging the role of family and friends respectively in this process. Written information provided at antenatal visits was perceived as useful by 35% of respondents. Digital resources provided a significant adjunct to the support provided by family, friends and health professionals. Most (95%) of the digitally active women searched websites and apps for information. Under half (45%) of women had websites or apps recommended to them by their midwife or doctor during antenatal visits and, of these, 91% referred to these resources. The Bounty app (<https://www.bounty.com/about-bounty/bounty-packs/bounty-apps>) was recommended the most, followed by the NHS website (<https://www.nhs.uk/>). Table 2 shows the websites and apps that women accessed during pregnancy. Education level appeared to play little part in women's online practices; 97% of women educated to degree level searched websites and 59-66% used apps for different purposes versus 93% and 61-68% respectively of those school/college educated.

Of the 596 women who used websites and apps in addition to their antenatal visits, 64% of women did so to learn about pregnancy changes and important warning signs *not previously discussed* with midwives or doctors; 41% used websites/apps to *confirm* information already provided by midwives or doctors; 39% used websites/apps but *did not discuss this* with midwives or doctors; 38% used websites/apps to find out *whether to share worries* with their midwife or how to get help if urgently required; and 30% used websites or apps *recommended* by their midwife or doctor.

Table 2. Routine access to helpful information about normal pregnancy related changes and signs of a complication on websites and apps

Use of different digital resources*	N=596 n (%)
NHS website (national or local)	498 (83.6)
Websites found via general search engines (Google, Yahoo etc.)	417 (70)
Symptom checkers e.g. WebMD, Mama Academy, Baby Centre, Tommy's	329 (55.2)
Social media sites e.g. Facebook, Twitter, Instagram, YouTube	176 (29.5)
Self-help groups/discussion groups/chat rooms	165 (27.7)

Other	54 (9.1)
Use of apps*	N=596
Pregnancy monitoring (tracking your own body changes)	357 (59.9)
Tracking normal baby development and growth	407 (68.3)
Access to pregnancy discussion/online forums	197 (33.1)
Tracking baby's movements	135 (22.7)
Tracking baby's heart beat	58 (9.7)
Other	26 (4.4)
Did not use apps	74 (12.4)
*Multiple options could be selected	

Experiencing health concerns and using symptom checkers to aid help-seeking

Over half (58%) of women experienced health concerns about their or their baby's health in the later stages of pregnancy (after 22 weeks). Of those who experienced concerns, 55% were primiparous and 61% multiparous. We provided a list of 8 red flags for women, with the option for them to select as many as applied (see Table 3). The top concern was fetal movement which was reported by 62%.

Twenty-five-nine percent of respondents reported 'other' concerns, including high blood pressure, renal and pelvic problems, and post-dates, position and size of the baby. Of those with concerns, 70% used websites and/or apps to help them understand the significance of these.

From the 678 responses, we found that women had used 91 different resources. Digital resources most often cited as enabling women to understand their concerns included: NHS website (mentioned 123 times/18%); Babycentre (<https://www.babycentre.co.uk/>) (mentioned 85 times/13%); and Bounty and social media (mentioned 55 times/8%). Respondents ranked their top three resources as NHS (160 times/25%), Babycentre (88 times/14%), Bounty (77 times/12%).

Table 3: Health concerns experienced during pregnancy

Health concerns about you or your baby's health after 22 weeks	N=632 n (%)
Yes	366 (57.9)
No	266 (42.1)
Type of concern*	N=366
Baby's movements	228 (62.3)
Pain in the stomach or upper abdomen	79 (21.6)
Feeling that something is not right	76 (20.8)

Mild of severe itching	54 (14.8)
Vaginal bleeding	46 (12.6)
Severe headaches	45 (12.3)
Blurred vision	26 (7.1)
Vomiting and diarrhoea	25 (6.8)
Other	105 (28.7)
Use of websites or apps to help understand the importance of women's concerns	N=366
Yes	255 (69.7)
No	111 (30.3)
<i>*Multiple options could be selected</i>	

Actions taken as a result of accessing digital resources (reported via free-text responses from 217 women), varied from seeking medical help (e.g. consulting midwife or, General Practitioner, attending Maternity assessment unit, AU, Accident & Emergency department, or hospital) (27%), taking no further action (6%), consulting further digital resources (0.9%), and speaking to friends and family (0.2%). Table 4 identifies the different forms of support women accessed to discuss the information retrieved or read online, and relationships between online resources and women's feelings. Women's responses to the resources were largely positive.

Table 4: Forms of support to help women make sense of the information found online

Who, if anyone did you discuss the information from websites/apps with?*	N=255 n (%)
Husband/partner	225 (88.2)
Midwife	156 (61.2)
Other family member	132 (51.8)
Friends	127 (49.8)
<u>General Practitioner / family doctor</u>	36 (14.1)
Pregnancy doctor (obstetrician)	35 (13.7)
Maternity helpline	21 (8.2)
Other medical professionals	14 (5.45)
Community networks	4 (1.6)
Did not discuss the information with anyone	8 (3.1)
Other	5 (2.0)
How did you feel after using websites/apps?*	N=255
More knowledgeable about signs and symptoms	220 (86.3)
More able to look after myself/my baby	135 (52.9)
More able to contribute to the consultation with midwives/doctors	118 (46.3)
Unsure what to do as different resources gave different advice	45 (17.6)

Worried about the information, and what action I needed to take	40 (15.7)
Confused about the information and what it meant	31 (12.2)
Unable to trust the information I found	22 (8.6)
Unsure how to discuss the information received with the midwife/doctor	9 (3.5)
Frustrated as I found no information helpful	7 (2.7)
Other	8 (3.1)
*Multiple options could be selected	

Of our respondents, 84% (309/366) sought help from a midwife or medical professional regarding health concerns. These were similar regardless of parity. Language did not appear to be a barrier to help-seeking (85% reported for both women with English and other languages as first language). The majority (79.5%) of those women who detailed how they perceived their concerns were attended to via free-text responses (292) reported feeling positive about the responses of midwives and medical professionals. Content analysis identified enabling response features (e.g. provision of reassurance; timeliness; concerns taken seriously) and influencing factors at clinical (e.g. rarity of condition), organisational (existing relationships with staff; differing responses within maternity staff teams; clinic busy-ness) and digital level (e.g. concordance between online advice and clinical advice received). For further detail see Supplementary information (Table S1).

DISCUSSION

Previous studies have focused on specific resources e.g. the internet (Daly et al., 2018; Grimes et al., 2014), social media (Johnson, 2014; Maslen & Lupton, 2019) or apps (Lupton, 2018) and specific applications e.g. screening for fetal abnormalities (Lowe et al., 2009) or perception of reduced fetal movements (Farrant & Heazell, 2016). In contrast, this study broadens its enquiry to women's blended use of digital resources to both learn about and self-diagnose/self-triage potential pregnancy complications as an adjunct to professional maternity services.

Study strengths include women from different geographical areas (London and the East Midlands), in urban and rural settings, and recruited via postnatal wards rather than postal survey or web-based/social media. Our respondents showed widespread IMD scores. The response rate (50%) is

comparable with similarly designed postnatal surveys (Grimes et al., 2014), although our rates reflect the limitations of recruitment from postnatal wards.

Our use of multiple methods (iPADs and paper versions) and bilingual research staff facilitated involvement of a diverse sample (including 2 women with poor literacy and 1 with a visual impairment). We note the lack of uptake of translational materials, and variable availability of bilingual research staff may have influenced our recruitment of women with limited understanding of spoken and written English. Our study suggests that to ensure inclusivity, considerable resources are needed in advocacy and outreach support to extend recruitment beyond those from majority cultural and language backgrounds (Johnstone & Kanitsaki, 2009).

Our findings extend understandings from simple binaries of digital access/no-access or use/no-use to understand the *range* and *type* of use (O'Neill, 2017). Only three respondents reported no access to digital devices, conversely, 95% used the internet daily. Respondents may have self-selected on the basis of digital literacy. We note our respondents reported a higher (34%) than national rate of previous pregnancy loss (Blohm et al., 2008; Manktelow et al., 2017) indicating a degree of selection bias on the basis of their previous experiences of pregnancy complications. However, our data reflect recent media use reports highlighting that smart phones are now integral to daily life (Ofcom, 2019), and that use is age related (1% of 16-34 year olds do not use the internet, rising to 4% in 35-44 range), although non-use is also driven by socio-economic group (23% in DE group) (Ofcom, 2019). Our data suggests education level and number of pregnancies exerts less influence on internet use and access among pregnant women comparative to previous studies (Sayakhov & Carolan-Olah, 2016).

Whilst women routinely used digital resources to supplement the information and support provided by family, friends and health professionals, there was much variability in the *types* of resource used. Some of this variability was linked to signposting of specific resources by health professionals at each site ([see Table S2](#)). This was in keeping with contextual data collected at two [of the sites](#). [At Site 3,](#)

~~where~~ staff reported women were routinely provided with Mama Academy wallets and signposted to the Bounty app ~~at Site 3~~, and at Site 2, staff reported that women were directed to resources on the hospital website ~~at Site 2~~. There was little evidence in the survey data to substantiate staff reports that women at Site 1 were routinely signposted to the Baby Buddy app. Whilst 84% of women found the NHS website helpful for finding out pregnancy related changes (both normal and abnormal), other resources were routinely also investigated, indicating women's use of a 'pic-n-mix' approach, as seen in other studies (Lagan et al., 2011). This pooling of resources allows cross-checking, but potentially adds a layer of interpretive work for women, particularly if there is variability in content between websites.

Our findings also link to reports of variability between more basic and complex online activities (Ofcom, 2019), as we distinguished between those who confined their activity to information retrieval and those who extend activity to include forms of self-monitoring via apps (Wallwiener et al., 2016). Safety concerns are increasingly raised by maternity providers and parent organisations over women's use of self-monitoring apps e.g. fetal dopplers ("Fetal Dopplers (Regulation) Bill (HC Bill 110)," 2017). Our data suggests that app use is no longer restricted to highly educated respondents relative to the general population (Lupton & Pedersen, 2016).

More than half of our respondents reported using websites/apps to learn about pregnancy changes and red flags because this information *was not previously discussed* with midwives or doctors. Digital resource use has been found to be influenced by professional and organisational factors such as decreased antenatal visits (Lagan et al., 2011), timing of visits (Kraschnewski et al., 2014), time pressures and reduced midwifery contact time and provision of individualised responsive care (Mackintosh et al., 2017; Peyton et al., 2014). Our findings also link to previous research highlighting that routine antenatal midwifery care, in an effort to avoid medicalisation of normal pregnancy and birth, may unintentionally lead to 'verbal asepsis' (Kirkham, 1989), limiting conversations about potential complications and warning signs (Mackintosh et al., 2017). Previous research has found that women wait for providers to initiate discussion about online information, and many

professionals do not incorporate discussion of these resources into clinical encounters (Diaz et al., 2002; Larsson, 2009; Sayakhot & Carolan-Olah, 2016; Slomian et al., 2017). Whilst healthcare professionals' openness to online information has a positive mediating influence on patients' trust and preparedness to share concerns (Tan & Goonawardene, 2017), women's digital engagement appears to remain largely separate and private, rather than being routinely incorporated into antenatal care.

Over 50% of respondents reported experiencing health concerns during the later stages of pregnancy (after 22 weeks). What we are unable to assess is how these experiences relate to routine online practices during pregnancy. Previous research has highlighted a relatively new phenomena, 'cyberchondria', which refers to the escalation of health anxiety prompted by internet searching (Fergus & Dolan, 2014; McMullan et al., 2019). Digital spaces can be filled with misinformation and contradictory information, creating confusion and anxiety for users (Aston et al., 2018). Digital resources offer potential for women to engage with 'anxiety about the unknown', inviting speculation over every potential pregnancy complication (Furedi, 2014). Information searching and retrieval can lead to further uncertainty. Digital resources may contribute to *increased* help-seeking as women turn to healthcare professionals to make sense of an online information vacuum from resultant heightened risk consciousness.

Of those with health concerns, 62% reported worries about fetal movement. There has been a recent policy and practice focus on supporting raising women's awareness of reduced fetal movements (RFM) as part of NHS [England](#) Saving Babies Lives care bundle (NHSE, 2017). Limited implementation data means effectiveness of this awareness raising strategy is difficult to assess (Flenady et al., 2019; Norman et al., 2018). Our survey highlights tensions in balancing the need for increased public awareness versus unintended public health consequences. Concerns have been raised that fetal movement awareness may lead to more harm than good (Walker et al., 2019), as women undertake self-monitoring activities (e.g. baby movement apps (Weller et al., 2018)), which may increase feelings of responsibility and anxiety (Faircloth & Murray, 2015).

Of the women with health concerns, 70% used digital resources to help with decision making. Our research highlights the socially contingent nature of help seeking. Husband/partners, friends and family helped women to self-diagnose and self-triage in response to online information and advice, suggesting that digital health education and public awareness campaigns must expand their messaging beyond individual women to the wider lay network.

When considering their health concerns, the majority of respondents found the various digital resources helpful at an individual level (enabling self-awareness and self-management), and collaborative level (enabling contribution during consultations with staff), suggesting the supplementary role of digital resources for escalation of care and shared decision-making. Between 8-12% of women also reported feeling confused or worried about what the information meant, or unsure what to do next. The low levels expressing concerns over trust in online information is surprising, given other higher reports (Ofcom, 2019); this could reflect the widespread use of NHS websites and professionally endorsed resources, such as Bounty. A variety of different digital resources were used by respondents, including several apps for fetal movement (e.g. Sprout and Ovia) which focus on “counting kicks” despite inconclusive evidence to support such recommendations (Daly et al., 2018).

A large percentage of respondents sought help from a healthcare professional about their health concerns. Given previous research and confidential enquiries reporting that some women’s concerns were disregarded by clinicians (Draper et al., 2015; Mackintosh et al., 2017; Rance et al., 2013), our survey results are encouraging, with 80% of women reporting feeling positive about responses received from staff. Free text responses indicated that what denotes a health concern and is seen as legitimate, in terms of professional help seeking, is influenced by many factors, including the degree of policy and social media attention, models of care and access pathways (Pope et al., 2019).

CONCLUSION

Online information retrieval and digital self-monitoring is increasingly part of women's self-care during pregnancy and enables escalation of care and shared decision-making. Further work is needed to assess optimal methods for staff to bring 'digital work' into clinical consultations in order to support women managing associated interpretive work, uncertainties and anxieties. Public health education programmes using digital platforms must move from individual behaviour change models to include partners and wider family members, who play an important role in women's sense and decision-making around help seeking. Further research is needed to establish how best to prepare staff to support women's digital use in pregnancy.

References

- Aston, M., Price, S., Monaghan, J., Sim, M., Hunter, A., & Little, V. (2018). Navigating and negotiating information and support: Experiences of first-time mothers. *Journal of Clinical Nursing*, 27(3-4), 640-649. doi:10.1111/jocn.13970
- Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., Kanouse, D.E., Muñoz, J. A., Puyol, J., Lara, M. (2001). Health information on the Internet: accessibility, quality, and readability in English and Spanish. *JAMA*, 285(20), 2612-2621.
- Blohm, F., Fridén, B., & Milsom, I. (2008). A prospective longitudinal population-based study of clinical miscarriage in an urban Swedish population. *BJOG: An International Journal of Obstetrics & Gynaecology*, 115(2), 176-183.
- Bounty. Retrieved from <https://www.bounty.com> retrieved 25TH March 2020
- Daly, L. M., Boyle, F. M., Gibbons, K., Le, H., Roberts, J., & Flenady, V. (2018). Mobile applications providing guidance about decreased fetal movement: Review and content analysis. *Women and Birth*. doi:<https://doi.org/10.1016/j.wombi.2018.07.020>
- Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., & Moulton, A. W. (2002). Patients' use of the Internet for medical information. *Journal of General Internal Medicine*, 17(3), 180-185.
- Draper, E., Kurinczuk, J., & Kenyon, S. E. (2015). *MBRRACE-UK Perinatal Confidential Enquiry: Term, singleton, normally formed, antepartum stillbirth*. Leicester. University of Leicester; 2015. on behalf of MBRRACE-UK.
- Eysenbach, G., Powell, J., Kuss, O., & Sa, E.-R. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. *JAMA*, 287(20), 2691-2700.
- Faircloth, C., & Murray, M. (2015). Parenting: Kinship, expertise, and anxiety. *Journal of Family Issues*, 36(9), 1115-1129.
- Farrant, K., & Heazell, A. E. (2016). Online information for women and their families regarding reduced fetal movements is of variable quality, readability and accountability. *Midwifery*.
- Fergus, T. A., & Dolan, S. L. (2014). Problematic internet use and internet searches for medical information: the role of health anxiety. *Cyberpsychology, Behavior, and Social Networking*, 17(12), 761-765.
- Fetal Dopplers (Regulation) Bill (HC Bill 110), Parliament UK (2017).
- Flenady, V., Ellwood, D., Bradford, B., Coory, M., Middleton, P., Gardener, G., et al. (2019). Beyond the headlines: Fetal movement awareness is an important stillbirth prevention strategy. *Women and Birth*, 32(1), 1-2. doi:<https://doi.org/10.1016/j.wombi.2018.12.001>

- Flenady, V., Wojcieszek, A. M., Middleton, P., Ellwood, D., Erwich, J. J., Coory, M., et al. (2016). Stillbirths: recall to action in high-income countries. *The Lancet*.
- Furedi, F. (2014). Foreward. In J. B. Ellie Lee, Charlotte Faircloth and Jan Macvarish (Ed.), *Parenting Culture Studies*. Hampshire, UK: Palgrave Macmillan.
- Garcia, J., Evans, J., & Reshaw, M. (2004). "Is there anything else you would like to tell Us"—Methodological Issues in the Use of Free-Text Comments from Postal Surveys. *Quality and Quantity*, 38(2), 113-125.
- Grimes, H. A., Forster, D. A., & Newton, M. S. (2014). Sources of information used by women during pregnancy to meet their information needs. *Midwifery*, 30(1), e26-e33. doi:http://dx.doi.org/10.1016/j.midw.2013.10.007
- Heazell, A. E., Siassakos, D., Blencowe, H., Burden, C., Bhutta, Z. A., Cacciatore, J., Dang, N., Das, J., Flenady, V., Gold, K. J. (2016). Stillbirths: economic and psychosocial consequences. *The Lancet*, 387(10018), 604-616.
- Johnson, S. (2014). "Maternal devices", social media and the self-management of pregnancy, mothering and child health. *Societies*, 4(2), 330-350.
- Johnstone, M.-J., & Kanitsaki, O. (2009). Engaging patients as safety partners: Some considerations for ensuring a culturally and linguistically appropriate approach. *Health Policy*, 90(1), 1-7.
- Kirkham, M. (1989). Midwives and information-giving during labour. In *Midwives, research and childbirth* (pp. 117-138): Springer.
- Kraschnewski, J. L., Chuang, C. H., Poole, E. S., Peyton, T., Blubaugh, I., Pauli, J., Feher, A., Reddy, M. (2014). Paging "Dr. Google": does technology fill the gap created by the prenatal care visit structure? Qualitative focus group study with pregnant women. *Journal of medical Internet research*, 16(6).
- Lagan, B. M., Sinclair, M., & Kernohan, W. G. (2011). What Is the Impact of the Internet on Decision-Making in Pregnancy? A Global Study. *Birth*, 38(4), 336-345.
- Larsson, M. (2009). A descriptive study of the use of the Internet by women seeking pregnancy-related information. *Midwifery*, 25(1), 14-20.
- Livingstone, S., & Helsper, E. (2007). Gradations in digital inclusion: Children, young people and the digital divide. *New Media & Society*, 9(4), 671-696.
- Lowe, P., Powell, J., Griffiths, F., Thorogood, M., & Locock, L. (2009). "Making it All Normal": The Role of the Internet in Problematic Pregnancy. *Qualitative Health Research*, 19(10), 1476-1484. doi:doi:10.1177/1049732309348368
- Lupton, D. (2013). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*, 11, 256-270.
- Lupton, D. (2018). Caring Dataveillance: Women's Use of Apps to Monitor Pregnancy and Children. In D. H. Lelia Green, Kylie Stevenson, Leslie Haddon and Tama Leaver (Ed.), *The Routledge Companion to Digital Media and Children*
- Lupton, D., & Pedersen, S. (2016). An Australian survey of women's use of pregnancy and parenting apps. *Women and Birth*, 29(4), 368-375.
- Mackintosh, N., Rance, S., Carter, W., & Sandall, J. (2017). Working for patient safety: a qualitative study of women's help-seeking during acute perinatal events. *BMC Pregnancy and Childbirth*, 17(1), 232.
- Manktelow, B., Smith, L., Prunet, C., Smith, P., Bobby, T., Hyman-Taylor, P., et al. (2017). *MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2015*. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester; 2017.
- Maslen, S., & Lupton, D. (2019). 'Keeping It Real': Women's Enactments of Lay Health Knowledges and Expertise on Facebook. *Sociology of Health & Illness*, 0(0). doi:10.1111/1467-9566.12982
- McMullan, R. D., Berle, D., Arnaez, S., & Starcevic, V. (2019). The relationships between health anxiety, online health information seeking, and cyberchondria: Systematic review and meta-analysis. *Journal of Affective Disorders*, 245, 270-278.

- Ministry of Housing, C. L. G. (2019). English indices of deprivation 2019. Retrieved from <http://imd-by-geo.opendatacommunities.org/imd/2019/area>
- NHS. NHS Website. Retrieved from <https://www.nhs.uk/> 24th March 2020
- NHSE. (2017). Saving Babies' Lives Care Bundle.
- Norman, J. E., Heazell, A. E. P., Rodriguez, A., Weir, C. J., Stock, S. J. E., Calderwood, C. J., et al. (2018). Awareness of fetal movements and care package to reduce fetal mortality (AFFIRM): a stepped wedge, cluster-randomised trial. *The Lancet*. doi:10.1016/S0140-6736(18)31543-5
- Nuzum, D., Meaney, S., & O'Donoghue, K. (2018). The impact of stillbirth on bereaved parents: A qualitative study. *PloS one*, 13(1), e0191635.
- O'Cathain, A., & Thomas, K. J. (2004). "Any other comments?" Open questions on questionnaires—a bane or a bonus to research? *BMC Medical Research Methodology*, 4(1), 25.
- O'Neill, B. (2017). Towards an improved understanding of modern health information ecology. *Social Science and Medicine*, 173, 108-109. doi:<http://dx.doi.org/10.1016/j.socscimed.2016.12.003>
- Ofcom. (2019). *Adults: Media use and attitudes report 2019*.
- ONS. (2019). *Internet users, UK: 2019*. Retrieved from <https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2019>
- Peyton, T., Poole, E., Reddy, M., Kraschnewski, J., & Chuang, C. (2014). *Every pregnancy is different: designing mHealth for the pregnancy ecology*. Paper presented at the Proceedings of the 2014 conference on Designing interactive systems.
- Pope, C., McKenna, G., Turnbull, J., Prichard, J., & Rogers, A. (2019). Navigating and making sense of urgent and emergency care processes and provision. *Health Expectations*, 22(3), 435-443. doi:10.1111/hex.12866
- Prescott, J., & Mackie, L. (2017). Correction: "You Sort of Go Down a Rabbit Hole... You're Just Going to Keep on Searching": A Qualitative Study of Searching Online for Pregnancy-Related Information During Pregnancy. *Journal of medical Internet research*, 19(7), e223.
- Rance, S., McCourt, C., Rayment, J., Mackintosh, N., Carter, W., Watson, K., & Sandall, J. (2013). Women's safety alerts in maternity care: is speaking up enough? *BMJ Quality & Safety*.
- Sayakhot, P., & Carolan-Olah, M. (2016). Internet use by pregnant women seeking pregnancy-related information: a systematic review. *BMC Pregnancy and Childbirth*, 16(1), 1.
- Shieh, C., Mays, R., McDaniel, A., & Yu, J. (2009). Health literacy and its association with the use of information sources and with barriers to information seeking in clinic-based pregnant women. *Health Care for Women International*, 30(11), 971-988.
- Sloman, J., Bruyère, O., Reginster, J.-Y., & Emonts, P. (2017). The internet as a source of information used by women after childbirth to meet their need for information: A web-based survey. *Midwifery*, 48, 46-52.
- Tan, S., & Goonawardene, N. (2017). Internet Health Information Seeking and the Patient-Physician Relationship: A Systematic Review. *J Med Internet Res*, 19(1), e9.
- Thomas, G. M., & Lupton, D. (2015). Threats and thrills: pregnancy apps, risk and consumption. *Health, Risk & Society*, 1-15.
- Tommy's charity. (2017). Movement Matters. Retrieved from <https://www.tommys.org/pregnancy-information/symptom-checker/baby-moving-less/movements-matter?> on 24th March 2020
- UN. (2014). *The State of the World's Midwifery 2014. A Universal Pathway. A Woman's Right to Health*. Retrieved from https://www.unfpa.org/sites/default/files/pub-pdf/EN_SoWMy2014_complete.pdf
- van Dijk, J. (2013). Inequalities in the Network Society. In K. Orton-Johnson & N. Prior (Eds.), *Digital Sociology. Critical Perspectives*. Hampshire, UK: Palgrave macmillan.
- Walker, K., Khan, K., & Thornton, J. (2019). Fetal movement awareness raising: more harm than good! *BMJ evidence-based medicine*, bmjebm-2019-111246.
- Wallwiener, S., Müller, M., Doster, A., Laserer, W., Reck, C., Pauluschke-Fröhlich, J., . . . Wallwiener, M. (2016). Pregnancy eHealth and mHealth: user proportions and characteristics of pregnant

- women using Web-based information sources—a cross-sectional study. *Archives of Gynecology and Obstetrics*, 294(5), 937-944.
- Warschauer, M. (2004). *Technology and social inclusion: Rethinking the digital divide*: MIT press.
- Weller, M., Gardener, G., Henry, S., Ellwood, D., Daly, L., Warrilow, K., . . . Flenady, V. (2018). My Baby's Movements: Integration of a mobile phone application into the antenatal education toolkit. *Women and Birth*, 31, S11. doi:<https://doi.org/10.1016/j.wombi.2018.08.040>
- WHO. (2016). *WHO recommendations on antenatal care for a positive pregnancy experience*. World Health Organisation; 2016.