MHealth resources for asthma and pregnancy care: methodological issues and social media recruitment. A discussion paper

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• Author contributions

Criteria	Author Initials
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Involved in drafting the manuscript or revising it critically for important intellectual content;	GRW, AO'C
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No conflict of interest has been declared by the author(s).

Abstract

Aims: A discussion of methodological issues and social media recruitment to a feasibility study to investigate mHealth resources for asthma and pregnancy care.

Background: pregnant women with asthma are reported to be poorly supported according to international research. We sought to establish if a mHealth intervention might be feasible and acceptable to them.

Design: a Phase I or modelling study.

Methods: A project team designed an intervention to address UK national guidelines for the management of asthma during pregnancy, using other resources already accessible on the web. This was made available on a project website optimized for mobile phone usage. Links were Tweeted and advertised on Facebook, asking participants to access the project website, which included links to the resources and before- and after-use questionnaires to establish baseline symptom data and participant views of the resources.

Results: Despite 55,700 Twitter impressions in a 76 day period over winter 2016-2017, this recruitment strategy garnered 402 engagements but only seven respondents for questionnaire 1 and zero respondents for questionnaire 2.

Conclusions: We could not recruit to this study despite believing that social media recruitment would be effective, and we recommend that social media recruitment be used cautiously. Apparently we did not sufficiently address theoretical aspects of communications theory and were not clear enough about our key messages. Publication bias may exist regarding the non-publication of other failed telemedicine studies using social media; this is goes largely unreported in some systematic reviews and may influence researchers' decision-making regarding social media recruitment.

SUMMARY STATEMENT

Why is this research needed?
- Asthma and pregnancy is a worrying time, with potential adverse consequences to mother and baby if exacerbations are not well controlled.

- International 21st century healthcare has embraced telemedicine and mHealth applications, which mean that people with many diseases can access specialist advice, care and support in novel and convenient ways, and at times when 'specialists' might otherwise be unavailable in person.
- We sought to investigate the feasibility and acceptability of a collection of web resources, recruiting via social media.

What are the key findings?
- Mass publicity using Twitter and Facebook appears 'easy' but we were unable to recruit participants to the study.
- Despite 55,700 Twitter impressions in a 76 day period over winter 2016-2017, this recruitment strategy garnered 402 engagements but single figure responses to only one of our questionnaires.

How should the findings be used to influence research?
- Despite its apparent ease, social media recruitment to research cannot be taken for granted.
- Researchers should consider carefully the purpose and content of the resources they develop, the linkages with communication theory and 'Why', 'What', 'How' and 'When' questions relating to their work.
- Literature detailing positive social media recruitment should not be accepted uncritically as it is possible that there is publication bias in the area, which goes largely unreported in some systematic reviews.

1. INTRODUCTION

This discussion paper is based on our own experiences in attempting to recruit pregnant asthmatic women for a feasibility study to investigate a care bundle of collected web resources. We discuss and reflect on these experiences, which are supported by literature and theory.

1.1 Background

Asthma during pregnancy can multiply the anxieties for women, who are likely to be anxious enough about their pregnancy (Blackmore et al. 2016). Women will have justified fears about the health of themselves and their baby, and are likely to have concerns that asthma exacerbations and the medications that they usually take might harm their baby (Beckmann 2002). It is clear that stopping usual medications is likely to be harmful (Belanger et al. 2010), that uncontrolled asthma is associated with numerous adverse perinatal outcomes for mother and baby (Enriquez et al. 2007), and that anxiety itself predisposes towards an asthma attack (Zhang et al. 2016). This clinical picture is complicated by the fact that it is established that during pregnancy, one third of pregnant asthma suffers' asthma will worsen, one third's will stay the same, and one third's will improve, and there seems to be little or no way of predicting accurately which individuals will be adversely affected (British Thoracic Society and Scottish Intercollegiate Guidelines Network, BTS/SIGN 2016).

Pregnant women become more likely to access health advice concerning their asthma when they are pregnant, which can improve confidence and improves health outcomes for non-pregnant adults with asthma where such advice includes education in asthma self-management, symptom self-monitoring, regular medical review and a written action plan, and understanding medications (Gibson et al. 2002). However, according to a recent systematic review, it appears that in clinical practice, asthma and pregnancy self-management is poorly understood and not effectively implemented, with less than a third of asthmatics in possession of a written asthma plan (Pinnock et al. 2015). Lack of a clear treatment escalation plan that is understood and negotiated with asthmatics is specifically implicated in the large number of UK deaths from asthma reported in 2104 in The National Review of Asthma Deaths (NRAD)(Levy 2014), which at 1.47/100,000 patients is the highest in Europe. Although NRAD does not mention pregnancy, may be emblematic of poor asthma care, at least in the UK.

1.2 Telemedicine and mHealth

Telemedicine or telehealth, are broadly defined as technologies, tools and services that facilitate 'virtual' communications between healthcare practitioners, and between healthcare practitioners and patients/clients/service users. They have been enthusiastically embraced as an adjunct to care (Smith et al. 2015) and have emerged as integral to international healthcare in the 21st century (Tuckson et al. 2017). More specifically, the use of mHealth (mobile health) has increased dramatically, and can be defined as health promotion, disease management and

behavioral change messages made available via text message, social media, and/or 'apps' (applications) for users of mobile devices such as phones and tablets (Bull and Ezeanochie 2016). Mobile applications that make access to health resources available 24 hours per day in synchronous and asynchronous formats (Olson and Thomas 2017) seem to offer revolutionary potential because, as well as facilitating communication in real-time: 'patients' can have access to expert knowledge without waiting until the 'expert' healthcare practitioner is available in person, and this reduces the impact of time factors as well as location. There is also great potential to reduce costs, reach large numbers of people via remote access and to standardize messages (Bull and Ezeanochie 2016).

Leaving aside the ethics of such advances and their quality assurance in terms of certification (Chan and Misra 2014) safety, confidentiality (Krieger 2013) and potential for product advertising, apps and other web-based resources have been shown to have benefits in systematic reviews across numerous health fields including: the treatment of lower back pain, where telemedicine interventions were superior to controls for improving quality of life, and were more beneficial than usual care alone in people with recent onset of symptoms (Dario et al. 2017); effective short-term smoking cessation (Ghorai et al. 2014); clinically important outcomes in type II diabetes management (Spyros et al. 2017); internet-based, text messaging, and smartphone apps to improve alcohol and substance abuse (Kazemi et al. 2017); text messages to improve medication adherence across several diseases (Anglada-Martinez et al. 2015; Dekoekkoek et al. 2015; Park et al. 2014); and feasible and acceptable resources with beneficial clinical outcomes in serious and enduring mental illness (Naslund et al. 2015), self-management of long-term illness (de Jongh et al. 2012) and contraception adherence (Smith et al. 2015). Most tellingly related to asthma and pregnancy, and for our study, although many studies relating to asthma and mHealth have been conducted with adolescents rather than adults, one systematic review indicated that mobile technology could improve adherence with asthma medications and was beneficial for self-management (Miller et al. 2017). MHealth has beneficial impacts on self-management in general lifestyle factors associated with pregnancy, according to some primary research studies (Naughton et al. 2017; Oliveira-Ciabati et al. 2017; Van Dijk et al. 2016), as well as reducing hospital admissions in those with more severe asthma (McLean et al. 2011).

Social media as a recruitment method in health-related research would appear to offer greater possibilities for recruiting larger numbers of participants in more dispersed geographical locations, with potential for complete privacy (O'Connor et al. 2014) , which therefore might also overcome a theoretical limitation of much health research which relies on local, face-to-face convenience sampling (Williamson 2003). Several studies indicate that social media including Twitter and Facebook increased sample size and was effective in recruiting 'hard to reach' groups including pregnant women (Adam et al. 2016; Admon et al. 2016; O'Connor et al. 2014).

Having already conducted a systematic review of the literature which indicated the need to reassure pregnant asthmatic women, educate them concerning how to self-manage their asthma and about their medications, with a population for whom little research has focused on their care as opposed to their medical treatment (Williamson et al. 2017), and that some midwives are unsure about their role in asthma management during pregnancy (McLaughlin et al. 2013), it seemed appropriate to investigate whether pregnant asthmatic women might value a 'care bundle' of collected web resources containing important and relevant information about their asthma during pregnancy.

2.0 THE STUDY

2.1 Aims
1. To investigate the feasibility and acceptability of the design of a care bundle of existing web-resources relating to asthma during pregnancy.
2. To explore aspects of participant recruitment via social media; specifically whether or not we could recruit participants to view our collected resources and evaluate them using our surveys, via Twitter and Facebook.

2.2 Design

This was designed as a Phase I or modelling study (Craig et al. 2008) in which we sought to investigate the feasibility and acceptability of this approach and our recruitment strategy.

2.3 Sample
Recruitment via social media appeared to be simple: using a Twitter account [@anitaoconnor2] our research assistant posted the following Tweet, and sent the Tweets in different forms, purposefully engaging with relevant Twitter-users and sites, including pregnancy-related twitter sites.
Can anyone help? I need women who've experienced #asthma in pregnancy to do 2 short surveys [@anitaoconnor2]... *Is that you?*

In addition, she set up a dedicated asthma and pregnancy Facebook page and posted information there repeatedly, with the following short message
> *Hi, we are researchers at Plymouth University and are trying to find women that have experienced asthma in pregnancy to do our 2 very short surveys. Could you please share our Asthma in Pregnancy page @asthmainpregnancy? If you would like more info please email me* [anita.oconnor@plymouth.ac.uk]. *Thank you.*

2.4 Data Collection

The project went live and the resources were made available on the project website optimized for mobile phone usage (see Appendix 1). A link to this site was Tweeted and advertised on Facebook, asking participants to access this project website. After participants had read the information sheet and watched the video, they were asked to click through to a SurveyMonkey questionnaire called The Baseline Asthma and Pregnancy Information Questionnaire (BAPIQ, see Appendix 2 for details) which asked 12 simple questions about their asthma and pregnancy, age, location and some basic questions about asthma symptoms, medications usage and their attitudes towards medications during pregnancy. A question establishing that potential participants had in fact had asthma during pregnancy was included at the beginning, and a 'no' answer to this meant that the rest of the survey could not be continued. Once the survey was completed, there was a link to the on-line resources we collected (PACTIV), and then a further link to the second questionnaire, to evaluate them (which we called the evaluation questionnaire the Asthma Care Team Intervention Questionnaire (ACTIVEQ, Appendix 3). This contained six questions about whether participants had looked at the resources and whether they were useful or not.

2.5 Ethical considerations
Ethical approval was granted by the university faculty research ethics committee.

2.6 Data analysis
Data analysis was not undertaken.

2.7 Validity and reliability
A project team including a Respiratory Nurse Specialist Matron, Consultant Respiratory Physician, an academic nurse with a respiratory background, and a patient representative, designed an intervention based on national guidelines (BTS/SIGN 2016) for the management of asthma during pregnancy, and other resources already accessible on the web. The project team had extensive clinical experience in this area over many years and had already undertaken their own research and systematic literature review into women's experiences with asthma and pregnancy (Chamberlain et al. 2014; Williamson et al. 2017). Ideas were discussed and agreed between the team in an iterative process by email and in face-to-face discussion. Patient involvement commentary came from one patient representative who had taken part in our original small qualitative research study (Chamberlain et al. 2014) and agreed to be involved again. A YouTube project video explaining the project was also made and was hosted in our dedicated web page. The resources and questionnaires were designed for the study and agreed within the team to have a high degree of face validity but these properties were not formally tested or intended to be tested in this design.

3.0 RESULTS

3.1 Twitter analytics
Between 10 November 2016 to 24 January 2017 Twitter analytics shows that the Tweet received 55, 700 Impressions (732 per day), which is the number of times users saw the Tweet on Twitter. This garnered 402 Engagements (the total number of times a user interacted with a Tweet, including clicking anywhere on the tweet e.g. hashtags, links, retweets, replies, follows and likes, see Appendix 4).

3.2 Facebook
The Facebook page received only one reply, offering to retweet the message.

3.3 Poor recruitment
Overall, despite the level of Twitter engagement, only seven people completed questionnaire 1 and zero people completed questionnaire 2.

4.0 DISCUSSION

4.1 Principal Results
Despite such extensive 'publicity' we managed only seven respondents to Questionnaire 1 and zero for questionnaire 2. We are unable therefore to conclude anything about the utility of the resources we collected and there is no benefit in reporting the findings from questionnaire 1 in this context. We are, however, able to conclude that whilst social media (specifically Twitter) was effective in getting a targeted message to the mobile phones or computers of a large number of people – 55,700 people in three months – we cannot know if they had asthma and pregnancy from the analytics that we have.

We may assume that those who engaged with the Tweets had at least an interest in the area, but we cannot know for certain; if we make this assumption, as we had 402 engagements of which seven people completed questionnaire 1, this would indicate the need for 57.4 interested people for one survey response, and this compares poorly with the research studies discussed in more detail below. Social media recruitment was ineffective in this study in a way that we simply did not anticipate. If we hypothesize that these 402 engagements were pregnant women of whom seven had asthma during their pregnancy, this equates to a percentage of 1.7, which again is poor considering that it is estimated that between 4% and 8% of pregnant women also have asthma (Katz and Sheiner 2008) and so we might have expected between 16 and 32 questionnaire respondents from these 402 engagements. Charlton et al. (2013) identified 12,828 women with asthma and pregnancy between 2000 and 2008 in the UK but while it is improbable that we could have

reached this number via Twitter and Facebook, our population may have been of a similar size.

4.2 Comparison with prior research

We had reason to believe that our recruitment strategy would be successful because social media recruitment has been effective in numerous studies in broadly related areas: for example, one study of antenatal older mother's experiences of care used a Twitter account to send a URL which took participants to an on-line survey, and in 11 weeks 749 tweets resulted in 299 mothers completing the survey (O'Connor et al. 2014). Our study had the same research assistant (AO'C) using the same strategy, but without such success. Similarly, using Facebook compared to face-to-face clinic recruitment to recruit pregnant women for a survey resulted in nearly five times the survey completion in the social media method (1178 women vs 219 women; Admon et al. 2016). In their discussion of recruiting pregnant women to clinical trials, one study (Mahvash et al. 2014) increased their recruitment from 35 women in 56 months to 45 women in 6 months when social media was involved, (a statistically significant difference in recruitment after the intervention of social media, P<0.0001).

Using Facebook for publicity seemed to have had a similar positive effect on recruitment, as one randomized controlled trial looking at perinatal outcomes (Adam et al. 2016) found an average rate of interest in their study of 0.3 women/day in 215 days of traditional recruiting compared to 2.8 women/day in the 26 days of Facebook recruiting, with a comparative approximate cost/eligible participant of Canadian $24 compared to Canadian $20 (respectively).

This ability to recruit more women than would otherwise be the case by traditional methods means that social media recruitment is frequently discussed as being cheaper, feasible, and quick as a means of recruiting a large sample of pregnant women, particularly for surveys (Eysenbach et al. 2016). In summary then, it seems as if pregnant women are amenable to being recruited to research studies via social media, but not to ours.

4.3 Limitations

One apparent criticism of mHealth research is that it has been shown to be largely atheoretical, or at least lacking much theoretical impetus (Bull and Ezeanochie 2016), so one reason for the limited recruitment to our study may be concerned with our failure sufficiently to articulate and therefore to address health communication theory, meaning we did not make clear enough to potential participants the gains and/or losses they might experience in using our resources, or how engagement might have given them support at times of need (Bull and Ezeanochie 2016). It seems as if behavioral intervention technologies (BITs) are rarely designed with an adequate conceptual framework that defines the clinical aim to the technological delivery, which is discussed (Mohr et al. 2014) as needing to answer the questions 'Why', 'What', 'How' and 'When'. The BIT model allows for a

clearer specification concerning who a treatment goal can be translated into a technology to deliver it successfully.

Indeed, we had not considered how our web materials could contribute to behavioral change, other than an anecdotal sense that they must: we knew from clinical guidelines (BTS/SIGN 2016) that one third of pregnant women's asthma must worsen, our previous research indicated that some women were caught out about by this and were not expecting or prepared to experience severe asthma of they had not done so before pregnancy (Chamberlain et al. 2014), and we knew that worsening asthma during pregnancy, particularly if associated with stopping medications, could have implications for the health and wellbeing of mother and baby (Murphy et al. 2006). Limited attention seems to have been focused on caring for asthmatic women during pregnancy, with little research evaluation of the potential benefits of individualized care (Williamson et al. 2017). A telemedicine intervention involving a management of asthma intervention with supportive telemedicine of respiratory function in pregnancy (MASTERY©), including a handheld respiratory device and an Android smart phone application (Breathe-easy©) and written asthma action plan demonstrated beneficial outcomes in asthma control interventions in pregnancy (Zairina et al. 2016); however, the wider evidence base for this type of intervention is limited. We responded to these needs by designing what we believed would be a useful collection resources, optimized for use on mobile phones, because we anticipated that anxious pregnant asthmatic women being able to access them out of hours for advice and support when they could not contact other health care professionals or were deciding about doing so; we specifically included access to an asthma self-management plan for this purpose as this is a recommendation from the UK national guidelines (BTS/SIGN 2016) and NRAD (Levy 2014) . However, it is clear from our lack of engagement that our assumptions concerning the utility of recruiting via social media for participants to examine their acceptability were flawed.

Had we used the BIT model (Mohr et al. 2014) in our resource design, we could have had more specifically answered the 'Why', 'What', 'How' and 'When' questions and this would have more clearly indicated some deficiencies that perhaps could have been rectified:

'Why' were our resources needed? It appears that informational care can avoid morbidity and mortality in poorly controlled asthma for pregnant women: this objective was sound; but we might have more clearly articulated this to potential participants.

'What' resources are needed? We collected existing resources and sought information as to whether this 'bundle' was acceptable, but could not recruit to the study, indicating that our recruitment method was flawed and/or the resources themselves were not satisfactory in some way. We could have been clearer about key messages here, perhaps focusing more closely on an asthma management plan and medications rather than the variety of materials we collected. However, as these

resources are available on-line anyway, it may be that potential participants simply used them without the need to engage with our research study. It may be that a collection of web-pages is not useful for pregnant asthmatic women but other forms of social media involvement like text messages might be.

'How' will behavioral change be accomplished? We failed to be specific about what we were trying to get participants to change in their own behavior, other than the acceptability of our care bundle. We suggest that this needs much more fuller articulation in future studies. Our intentions included education and reassurance, but we failed to address other important issues including making sure that potential users set clear goals, assessed their state of health and monitored improvements, and we did not offer motivation for them to do so.

'When' would are resources be useful? We had envisaged them as an informational resource useful perhaps out-of-hours or at night when a woman might be anxious about worsening symptoms and need reassurance or encouragement to contact emergency services, or as a support in decision making regarding using medications. These are three quite different objectives and arguably were not clearly addressed in our collection of web resources: there was just too much in there for our participants to take on board (see Appendix 1); too broad an intention which translated into lack of clarity.

To summarize, more explicit linkage with communications theory and more effective planning may have made these collected resources more useful to potential participants, and that might have been reflected in more effective recruitment to our study (Bull and Ezeanochie 2016; Mohr et al. 2014). However, as we designed them in this study, this collection of web-pages was not useful for pregnant asthmatic women. We can speculate that other forms of social media involvement like text messages to support health behaviours relating to understanding and maintaining medications, using an asthma self-management plan and knowing when to seek medical help might be of more, particularly as text messaging has been useful in other health fields (Anglada-Martinez et al. 2015; Dekoekkoek et al. 2015; de Jongh et al. 2012; Smith et al. 2015).

4.4 Publication bias?

One other possibility that is worth exploring is the extent to which publication bias might be an issue in mHealth studies. Publication bias is most frequently discussed as a feature involving non-submission of negative results to journals, but can also be seen after submission where reviewers or journal editors inhibit publication of certain types of studies or results (Strüver 2016). Publication bias is most commonly assessed using funnel plots in systematic reviews, which can indicate the absence of publications, as well as exaggeration of treatment effects in small studies (Sterne et al. 2001). It is impossible to know the extent of publication bias in this field without conducting a full systematic review of the genre, and this is beyond the scope of this paper. However, and whilst the systematic reviews discussed above in

the context of social media recruiting in mHealth (Anglada-Martinez et al. 2015; Dario et al. 2017; de Jongh et al. 2012; Dekoekkoek et al. 2015; Ghorai et al. 2014; Kazemi et al. 2017; Naslund et al. 2015; Spyros et al. 2017) is a limited and non-systematic sample of the literature and therefore necessarily representative, it is worth noting that only two (Smith et al. 2015; Spyros et al. 2017) discussed fully the issue of publication bias and none were able to construct funnel plots. It may be the case therefore, that publication bias has coloured the debate about the efficacy of social media recruitment to some extent, because the studies that get published are the ones where it has been effective. However, this is a speculative conclusion and cannot be asserted with any accuracy, but it is clear that future systematic reviews should address more clearly the issue of publication bias in case social media recruitment is not as unproblematic as it currently appears.

5. CONCLUSIONS
This study sought to discover whether or not a collection of existing web-resources for asthma during pregnancy were feasible and acceptable to pregnant asthmatic women, and to explore aspects of social media recruitment; we had theorized that such resources might be useful in reassuring pregnant asthmatic women and help them learn about asthma self-management plans and medications, which are under-utilized in the UK (Levy 2014) despite clear national guidelines (BTS/SIGN 2016). Unfortunately we did not recruit more than seven questionnaire respondents, which tells us that the web resources we collected were probably not useful in the format in which we made them available. It would seem that they were not feasible and acceptable: although we had no specific data about this it is a fair assumption that they did not motivate people to complete the questionnaires. It is much clearer, however, that social media in the form of Twitter and Facebook were not successful as a recruitment strategy in this study despite a wealth of evidence that they have been useful for others (O'Connor et al. 2014).

Publication bias in previous studies with successful social media recruitment is a possibility and may have coloured our thinking about this as a strategy, but it is also probable that a primary reason for our lack of success concerned our failure to sufficiently articulate the purpose of our study: the women we sought to recruit possibly could not see the benefits in what we were asking them to do, as they could access the resources without helping us by getting involved in the study. It may be that text messaging might be a more effective means of engaging with pregnant asthmatic women, as it has been shown that targeted telemedicine interventions are effective in asthma control amongst pregnant women (Zairina et al. 2016), including an asthma management plan. One recommendation therefore would be that future research examines mHealth and telemedicine interventions above and beyond static webpages, to include text messaging from a source identifiable as a respiratory professional. A second recommendation is that future systematic reviews of mHealth interventions specifically address the issue of publication bias; if funnel plots are not possible, then authors should include some narrative account and discussion of potential publication bias. A third recommendation is that journals

publish studies with non-significant findings or poor recruit via social media, which would help to inform researchers that this is not as uncomplicated and successful as it may initially appear.

Despite its apparent ease, social media recruitment to research cannot be taken for granted, and it may be that there is publication bias in the field. Researchers should consider the influence of communication theory when designing their applications, and 'Why', 'What', 'How' and 'When' questions relating to their work.

Supporting material
1. Appendix 1: Screen shot of project website
2. Appendix 2:
3. Appendix 3:
4. Appendix 4: Twitter analytics

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Appendix 1: Screen shot of project website