Participant Information Sheet

Study title
Focus groups to co-develop a primary care intervention to promote engagement in an online health community (OHC) for adults with asthma, a survey to recruit participants and a non-randomised feasibility study testing recruitment and the intervention - *Feasibility study*.

Research team
Dr Anna De Simoni (Chief Investigator), Professor Chris Griffiths (Sub-investigator), Dr Helen Wood (Programme Manager), Dr Georgios Karampatakis (Postdoctoral Researcher).
NHS REC reference: 22/NE/0182
IRAS ID: 314672

Invitation paragraph

You are being invited to participate in a research study. Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us questions if there is anything that is not clear or if you would like more information.

What is the purpose of the study and what would taking part involve?

Previous research has found that joining an online health community may help asthma patients to control their asthma better. However, the potential and safety of online peer support (i.e. support from other people with asthma) when formally integrated into primary care services has not been studied. We have recently developed an online intervention for patients with troublesome asthma. Our intervention involves a structured consultation with a GP or practice nurse to promote online peer support via engagement in the online health community run by the charity Asthma + Lung UK. The aim of this study is to refine our intervention and test the feasibility of carrying out a large trial to assess its effectiveness in helping patients with troublesome asthma.

We are inviting you to take part in a feasibility study, which will consist of the intervention delivery, collection of some follow-up measures and, possibly, a research interview.

You will be contacted (over the telephone or via email) by a GP/practice nurse at the GP practice where you are registered to schedule a consultation, either in person at the GP surgery or online (via Zoom or QMUL approved software), if you prefer. During the

consultation, a GP or practice nurse will deliver the intervention and sign you up to the online health community run by the charity Asthma + Lung UK. They will also complete an online questionnaire with you. The consultation will last around 30 minutes.

About three months after the consultation, you will receive a text message or email with a link to an online, short questionnaire (or alternatively, you can request a paper copy of the questionnaire and return it by post). This online questionnaire will ask you to provide some follow-up measures regarding your engagement with online peer support throughout that period, as well as your asthma and other associated long-term conditions you may have. It should take no longer than 15 minutes to complete.

You may also be invited to a one-to-one interview with a member of the research team. The interview will be scheduled on a convenient day and time for you, will take place either at your GP practice or virtually, and will last for about 90 minutes. During the interview, the researcher will ask you some open-ended questions to explore your experiences of the intervention. There are no right or wrong answers – we are interested to hear your views and opinions.

Why am I being invited?

You are being invited to participate in this research study because:
-You are a patient with troublesome asthma, registered with a GP practice in North or East London (where the study is taking place) and
-You have indicated, in an earlier survey study, your willingness to receive the intervention and have provided us with your contact details.

Do I have to take part?

No. This participant information sheet has been written to help you decide if you would like to take part. It is up to you whether you wish to take part. If you do decide to take part you will be free to withdraw at any time without needing to provide a reason, and with no penalties or detrimental effects.

What information about me is going to be collected?

You will be asked to sign a consent form by providing your full name and signature, at the time of the consultation with the GP or practice nurse and at the beginning of the one-to-one interview with a researcher (if invited). Three months after receiving the intervention, you will be asked to report a few measures in relation to the severity of your asthma and associated long-term conditions, a few measures of your overall health, and the amount of your engagement with online peer support. With your permission, we will access your NHS GP and hospital records and other registers (e.g. NHS Digital) to collect information about your use of these services and any asthma exacerbations in the three months after you receive the intervention. Collection of anonymous data relating to your health and healthcare use is necessary to test the feasibility of obtaining valid data and performing certain types of analyses. With your permission, we will access and analyse your interactions with other peers in the online platform (including your posts, but not private messages) to understand the intervention's potential to create networks of communication and support, as well as information exchange amongst peers. Again with your permission, the interview discussion will be audio-recorded (should you be invited to attend a research interview).

What are the possible benefits of taking part?

There are no direct benefits of taking part. You may find, however, that you are able to cope better with your asthma after receiving the intervention. You will also be contributing to the development of an intervention that might ultimately help a large number of patients to manage their asthma.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks of taking part. The main disadvantage to taking part is that it will take some of your time. Receipt of the intervention, or refusal to do so, will not affect the normal treatment or care that you would have otherwise received. The online health community run by the charity Asthma + Lung UK is a well-established, well-moderated platform. You can decide how much you interact and share with the online community and what information you share with us (the option will be thoroughly explained to you during the consultation). You are free to withdraw from the study at any stage, without giving a reason. If you do not want your voice to be audio-recorded during the interview at the end of the study, you can ask the interviewer to keep detailed notes of your individual points instead.

Expenses and payments

We will reimburse the transport to the general practice to attend the consultation by offering you £10 in the form of a supermarket voucher. Should you attend a research interview, we will offer you £30 (again in the form of a supermarket voucher) as a compensation for your time. Compensations are the same for all participants.

When and how will my data be destroyed?

Your consent form(s) will be retained until data publication and will then be destroyed by shredding and disposal as confidential data. Your contact details and any personal identifiable data will also be destroyed/deleted after data publication. According to QMUL policies, data from research studies should be retained for 5 years. After data publication, anonymous data will be archived in the Corporate Records Facility at 9 Prescot Street, London, E1 8PR (which is the QMUL data repository) and will be safely disposed as per QMUL policies and in line with the above-mentioned timeline.

How will we use information about you?

We will need to use information from you and your medical records for this research project.

This information will include your

- Name and contact details
- Demographic and health-related details
- Use of healthcare services.

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

All the information we collect about you will be stored safely and securely at Queen Mary University of London, according to the University's data protection guidelines..

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

- You can stop being part of the study at any time, by emailing ADHOC@qmul.ac.uk and without giving a reason, but we will keep information about you that we already have.
- If you choose to stop taking part in the study, we would like to continue collecting information about your health from your NHS GP and hospital health records. If you do not want this to happen, tell us and we will stop.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can I find out more about how my information is to be used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to QM: data-protection@qmul.ac.uk
- by ringing us on 0207 882 2520 (voicemail).

Who is organising and funding the study?

The study is part of a larger programme of work, funded by the National Institute for Health and Care Research and sponsored by QMUL, and is organised by researchers at the Centre for Primary Care at QMUL.

Who has reviewed the study?

This study has been reviewed by an NHS Research Ethics Committee and the Health Research Authority (Integrated Research Application System Project ID: 314672) and has been approved.

What should I do if I have any concerns about this study?

If you have any concerns about how the study was conducted, in the first instance, please contact any of the researchers listed below. If you have a complaint which you feel you cannot discuss with the researchers, please contact Patient Advice Liaisons Service (PALS) – LOCALISED INFO TO BE ADDED.

Who can I contact if I have any questions about this study?

For questions about the study, please email ADHOC@qmul.ac.uk or contact one of the researchers below.

Dr Anna De Simoni, Chief Investigator
Email: a.desimoni@qmul.ac.uk
Voicemail: 0207 882 2520

Dr Georgios Karampatakis, Postdoctoral Researcher
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Thank you for reading this information sheet