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## 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 - Survey study.

### Research team

Dr Anna De Simoni (Chief Investigator), Professor Chris Griffiths (Sub-investigator), Dr Helen Wood (Programme Manager), Dr Georgios Karamatakis (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 taking part in an online health community may help asthma patients to control their asthma better. We would like to test this in a large group of asthma patients, by offering them an intervention that involves using the online health community run by the charity Asthma + Lung UK. We would like the help and input of asthma patients to understand the characteristics of people who would potentially be interested in this type of intervention, versus those who would not.

We are inviting you to complete an online survey, which will take around 15 minutes. To access the survey, please click on the following link [\[insert link\]](#) and follow the instructions provided. Completion of the survey will imply that you understand the information in this leaflet and that you have agreed to take part. No separate written consent will be required. Please complete the survey within one month from the date you received the text message invitation from your GP practice. You will receive a reminder text message, again from your GP practice, one week before the survey's closing date.

The survey asks for some brief demographic and socioeconomic data, some details about your asthma and other associated long-term conditions you may have, as well as your overall health, and some details about who supports you in self-managing your asthma (including



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whether you would consider seeking online support from other patients with asthma). Please try to be as honest as possible when answering these questions.

The survey also asks if you would be willing to take part in the next stage of our research programme. This will be a small study to try out an online intervention designed to help asthma patients better self-manage their asthma. It would involve attending a 30-minute consultation with a doctor or nurse or pharmacist at your GP practice, during which you would be signed up to the online health community run by the charity Asthma + Lung UK. If you would consider taking part in this study, please tick 'yes' when asked in the survey and we will send you some further information. Ticking 'yes' does not commit you to taking part – you can decide once you have read the further information.

### **Why am I being invited?**

You are being invited to participate in this survey study because you are a patient with asthma, registered with a GP practice in North or East London.

### **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 are the possible benefits of taking part?**

There are no direct benefits of taking part, other than contributing to the development of an intervention that might eventually be used in GP practices as part of asthma reviews.

### **What are the possible disadvantages and risks of taking part?**

There are no foreseeable risks of taking part. The main disadvantage to taking part in the study is that it will take some of your time (around 15 minutes). If you find it difficult to complete the survey online, you can request a paper copy and return it by post. It is possible that you may find answering some of the questions challenging. This is unlikely, but you can skip any questions that you do not want to answer or decide not to complete the survey.

### **Expenses and payments**

Please note that there will be no compensation for participating in this study.

### **What information about me will be collected?**

The survey includes questions about your age group, ethnicity, gender, education and qualifications, annual income, the severity of your asthma and associated long-term conditions, your overall health, and your understanding of health and disease. We will also ask you for permission to link your survey data to routinely collected health information held in your NHS GP and hospital records and NHS Digital. This information will help to understand



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whether the study intervention help patients managing their asthma better and avoid worsening of symptoms. Participation in the survey will be anonymous.

### **When and how will my data be destroyed?**

According to QMUL policies, data from research studies should be retained for 5 years. After publication, anonymous data will be archived in the Corporate Records Facility at 9 Prescott Street, London, E1 8PR (which is the QMUL data repository) and will be safely disposed in line with the above-mentioned timeline. Contact details will be held until completion of the online intervention study (in about one year from now) and will then be deleted.

### **How will my information be used?**

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

This information will include your name and some of your health-related details. 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](mailto:ADHOC@qmul.ac.uk) and without giving a reason, but we will keep information about you that we already have.
- 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 used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://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](mailto:data-protection@qmul.ac.uk)
- by ringing us on 0207 882 2520 (voicemail).

### **Who is organising and funding the study?**



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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 the manner in which 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](mailto:ADHOC@qmul.ac.uk) or contact one of the researchers below.

Dr Anna De Simoni, Chief Investigator

Email: [a.desimoni@qmul.ac.uk](mailto:a.desimoni@qmul.ac.uk)

Voicemail: 0207 882 2520

Dr Georgios Karampatakis, Postdoctoral Researcher

Email: [g.karampatakis@qmul.ac.uk](mailto:g.karampatakis@qmul.ac.uk)

**Thank you for reading this information sheet**