

# Patient Newsletter

**Thank you to everyone who has taken part in BLISS so far! Without your help and support this study would not be possible.**

## Aims of the BLISS Cohort study

The main aims of the study are to develop tools which will allow doctors to better manage patients who have, or are at risk of, lung disease (COPD) and to improve our understanding of the development and progression of the condition.



## Additional questionnaire

We have sent an additional questionnaire with this newsletter, to everyone who agreed to be contacted about future research. This will help us plan future interventions that may help people with lung problems, and we are keen to ensure your contact details are still correct.

***By returning the questionnaire you will be entered into a prize draw for one of three £100 Marks & Spencer vouchers!***

## Using your Data

As you may remember, in 2014 we sent a letter outlining plans to access information about your hospital usage. The organisation providing this data to us was at that time called the 'Health and Social Care Information Centre (HSCIC)' but they are now called 'NHS Digital'. As explained previously we need this data to look at the likelihood of patients visiting or being admitted to hospital as a result of their lung health. The information we will be obtaining, for everyone that participated in the Birmingham COPD Cohort study, relates to hospitalisations for any reason and includes the number of hospital visits or admissions, reason for admissions, length of stays and treatments received. NHS Digital will also provide us with information about study participants who may have passed away since the start of our study, including date and cause of death. The data we obtain will be stored at the University of Birmingham, and used only for the purposes of the study by researchers employed by the University.

We can access all of this through hospital records by securely sharing some of your personal details, specifically your name, date of birth and NHS number, with NHS Digital who then provides us with the information described above. Importantly, no other information that might identify participants will be shared with the BLISS team and no identifiable patient data will be used in any publication or presentation. If you would like to discuss this or have any questions, please contact us. We intend to share your data with NHS Digital in early 2017 in the first instance.

If you prefer us not to access your information in this way, please let us know either by e-mail, letter or telephone using the contact details on this newsletter. We will not share your information if you have already opted out. If you choose to opt-out after we share your information, we will destroy your data received from NHS Digital. For any further updates, please see our website ([www.birmingham.ac.uk/bliss](http://www.birmingham.ac.uk/bliss)).

## Current and upcoming projects



### E-cigarettes: calling for ex-smokers who have COPD

We are currently conducting telephone interviews to explore patients' views about e-cigarettes. The study is going well and we are now particularly keen to interview patients with COPD who have quit smoking in the last 3 years. If you have quit smoking in the last 3 years and would be interested in taking part, please contact us using the below details. Those who take part will receive a £15 love2shop voucher as a thank you for your time!



### Phase 2 of TargetCOPD and the Cohort study

Some of you were involved in the TargetCOPD study, which has now been extended to look at whether early detection of COPD affects hospitalisation and mortality rates. We also hope to extend the Cohort study to look at lung health over a longer period of time, and we may contact you at a later date to see if you are happy to continue.



## Recent publications

You can read the results of some of our work by accessing the below articles online. We will also be publishing more in the coming months, so look out for more information in future newsletters!

- Summary of TargetCOPD trial: <https://discover.dc.nihr.ac.uk/portal/article/40000438/questionnaires-directed-at-smokers-improve-detection-of-chronic-lung-disease-in-general-practice>
- Adab et al (2016) International Journal of Epidemiology "Cohort Profile: The Birmingham Chronic Obstructive Pulmonary Disease (COPD) Cohort Study"

## Withdrawal from the Birmingham COPD Cohort study

We hope you will not wish to withdraw from the Cohort study, because the project is of most value if participants continue to provide data and stay with the project. However, participants can withdraw at any time without providing a reason. You can withdraw by phone, email or letter.

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### Any suggestions?

What would you like to see in the newsletter?  
Please get in touch with us we'd love to hear  
your ideas!

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