

Liverpool Healthy Lung Programme

Information

- **How we use and store your data**
- **Asking your permission (consent) to share some of your data**

Liverpool Healthy Lung is a new NHS programme in the city. It is designed to help us find lung disease earlier. We want to see how well this programme works and whether people are happy with it. We want to share what we learn with the NHS.

This leaflet explains how we use and store your information for your health care

This leaflet also asks you to consider if we can share some of your information to help us learn whether the Healthy Lung programme has worked.

1. How is the NHS using your data (name, address, date of birth, telephone number, gender) to invite you to a Lung Health Check?

GPs in Liverpool have made a list of patients to be invited to attend a lung health clinic. This list has been shared with NHS Liverpool Clinical Commissioning Group (NHS LCCG).

- NHS LCCG is responsible for planning NHS services across the city.
- NHS LCCG is organising the lung health clinic service on behalf of all GP practices and all hospitals in the city.
- NHS LCCG is an NHS organisation, which keeps all data securely in line with NHS data requirements.

GPs have shared names, addresses, dates of birth, telephone numbers and whether you are male/ female with NHS LCCG for everyone invited to lung health clinics. This means NHS LCCG can book appointments with people who want to come to a lung health clinic.

GPs have not shared any clinical information about your health, or additional personal information, with NHS LCCG.

GPs have shared this list securely, through a computer system called 'EMIS' (Egton Medical Information Systems). EMIS is the system that GPs use in primary care.

2. How will NHS Liverpool CCG store your information:

If you come to a lung health clinic, information collected about you during and after your appointment (your clinical records) will be held by NHS LCCG. Clinical records are held by your GP, hospitals, and community NHS services, such as District Nurses. Because this is

a new NHS service, we are asking you if NHS LCCG can hold clinical records about your lung health.

The records will include basic details about you, such as your name and address. They may also contain more sensitive information about your lung health and also information such as outcomes of tests.

We may keep your information in written form and/or on a computer. The computer system we will use is the same as your GP's system: EMIS.

NHS LCCG will not publish any information that identifies you or disclose any information about you without your express permission. At any time you have the right to refuse/withdraw consent for us to hold your information.

Anyone who receives information from us is also under a legal duty to keep this information confidential.

Everyone working for the NHS is subject to the Common Law Duty of Confidence. The information we do hold about you, whether in paper or electronic form, is protected from unauthorised access. Under the NHS Confidentiality Code of Conduct, all our staff are required to protect your information, inform you of how your information will be used, and allow you to decide if and how your information can be shared.

Under the Data Protection Act 1998 you have the right to see or be given a copy of personal information held about you. You can do this by submitting a Subject Access Request (SAR) to the NHS LCCG.

If you believe the NHS LCCG has not complied with the Information Protection Act, either in responding to a Subject Access Request or in the way we have processed your personal information, you have the right to complain by contacting the National Information Commissioner's Office.

If you do not wish us to store information about you, this will not affect your care or treatment in any way. You will still be able to take part in the Healthy Lung Programme. In this case we would keep information about you only as long as necessary for your care, e.g. until your appointment/referral/treatment was completed, and then we will transfer all records to your GP in full.

3. How will my information be used?

- **It will be used for your care:**

The information collected by the lung nurses will be stored on EMIS (the same system all GP's in Liverpool use).

If you attend your GP Practice for something else, the information collected by the lung nurses is available to the GP. Your clinical information will be shared with NHS hospital and community services as part of routine care.

- **We want to know if this programme works:**

This programme is new.

We have asked organisations to work with NHS LCCG to review how we are doing in finding and treating lung disease earlier and better.

NHS LCCG is working with the following organisations :

- an independent body - to help us decide if the programme has worked in Liverpool. We will share anonymous data about all participants, but you cannot be identified from what we will share. We will receive a report for NHS LCCG about the success of this programme in 2017.
- Queen Mary University London - they are running a national NHS Programme (ACE Programme), examining ways of providing better diagnosis and care for lung cancer. They are working across several regions of England. . They would like to compare our work in Liverpool with different approaches in other cities. We want to support their work, to help us interpret our local findings better. We will share anonymous information with Queen Mary University London. We won't share anything which could identify you, e.g. your name, address, date of birth. They will recommend if similar services should be set up in other areas of England.

4. **We would like to share your data – and we are asking you for permission to do this. You do not have to agree to share your data.**

We are asking you if we can share your data with the **Roy Castle Lung Cancer Research Programme, University of Liverpool**

We would like to share information with researchers at Roy Castle Lung Cancer Research Programme, in the University of Liverpool Cancer Research Centre. They will match records of people who take part in the Liverpool Healthy Lung Programme with the Office of National Statistics, the England Cancer Registry and the NHS Hospital Episode Statistics database. If you agree, NHS LCCG will share your NHS number, your date of birth, postcode and clinical information collected by the Liverpool Healthy Lung Programme, with the University of Liverpool team. They can then link this information with other national information. Once the pieces of information have been joined together, all further analysis will be done anonymously. You will not be identified in any of the results.

The information will be compared with the UK Lung Cancer Screening (UKLS)¹ trial information from Liverpool. This will help to further develop the lung cancer risk tool used in our Healthy Lung clinics. It will help to assess health inequalities in people at risk of lung cancer. It will also help to see how information from lung CT scan reports can help to understand other health conditions.

During and after you take part in the Liverpool Healthy Lung Programme, Liverpool University would like to see how you are. They will access information from your medical records, your GP, NHS Central Register, The Health and Social Care Information Centre, the Office of National Statistics (mortality data) and local medical registers. This data will help to influence the University's research It may include:

- (i) your medical notes (e.g. the results of hospital tests, types of diagnosis and any treatment you receive),
- (ii) Cancer Registries, which provide details of any cancer you might suffer after taking part in Liverpool Healthy Liverpool Lung. This is important information because it allows the University to find new ways of predicting lung cancer – using the data and samples you have provided,
- (iii) the Office of National Statistics (ONS), which provides information about dates and causes of death (mortality data) – this is important because the University is interested in what happens to you after you have taken part in Liverpool Healthy Lung.

Data will be stored in accordance with the Data Sharing Agreement with the NHS, and in accordance with the law.

5. Is my information safe?

Yes. All the information that is collected about you during the study will be kept strictly confidential in accordance with the Data Protection Act 1998.

Any information held locally is stored in the same way as your GP data, on the same computer system.

NHS LCCG has formal Information Sharing Agreements for any information we share with other organisations.

NHS LCCG is working with organisations who are very experienced in this type of evaluation, and who handle large amounts of health information. They have a track record in making sure that information is held safely. The organisations the NHS is working with have signed an agreement with the NHS to make sure the information is only used for the reasons you have agreed to.

¹ <http://www.ukls.org/index.html> UK Lung Screening Trial

Your information will not be sold or used for any marketing purposes.

For further information please contact:

Liverpool Healthy Lung clinical team – 0151 254 3032 or NHS Liverpool Clinical Commissioning Group via healthylung@liverpoolccg.nhs.uk.