

Do you have Chronic Obstructive Pulmonary Disease (COPD)?

Do you want to shape the future of COPD care?

Overview

Birmingham Heartlands Hospital part of University Hospitals NHS Foundation Trust is excited to be partnering with local healthcare providers to evaluate the quality of care patients with COPD receive in different healthcare settings.

What do we hope to achieve with this project?

We have set ourselves a number of goals, which include:

- Comparing respiratory specialist care in the primary care setting with 'usual' care for patients with COPD, to determine if patients with COPD are receiving care which follows current guidelines.
- Evaluating if guideline based care leads to better health outcomes for patients with COPD.
- Determining if respiratory specialist care leads to improved quality of life for patients with COPD.

Who is involved?

The project is a partnership between:

- Birmingham Heartlands Hospital who will provide leadership to the project, as well as clinical input, academic oversight and technical support.
- Local participating GPs, who will play a key role in recruiting patient and will contribute with clinical input and leadership.

What is our starting point?

This study will look at the quality of care patients with COPD receive in the primary care setting. In particular, this study will compare respiratory specialist care to 'usual care'. This data will be used to answer a number of research questions, which in turn will allow us to identify changes that should bring benefits to those living with COPD. We will publish our findings in research journals and share these at academic conferences, so that a broader audience can learn from our research. These findings will also be available on the hospital website.

How will the data be collected?

General practices already routinely collect treatment data which we have identified as being vital to evaluating the quality of care patients with COPD receive. For the purposes of this study, this information will be extracted by NHS IT staff in each participating NHS organisation. Before the data is securely transmitted to a special research database, the IT staff will carry out a number of processes to ensure it is not identifiable to anyone outside their organisation. This process (which is called 'pseudonymisation') replaces identifiable information (such as name, address and date of birth) with versions that do not allow the individual to be identified. The data will also be encrypted on our secure server where access will be restricted to designated individuals.

What if I do not want to participate?

If you would rather not participate in the project, please inform your GP to ensure that your data will be excluded from all future analysis. You can choose to opt out at any time. If you opt-out, your information will remain confidential and will not be used in any further future data analysis undertaken as part of this project. In order to ensure your data is successfully excluded, and not accidentally re-incorporated at a future date, we will maintain a list of the codenames for patients that have opted out – these codenames will be unidentifiable outside of the NHS.

What type of data will you collect?

This project will focus on patients with COPD. The information we collect will focus on the care patients with COPD receive including tests and treatments (e.g. clinic appointments, laboratory tests, scans, prescriptions), and their outcomes (e.g. lung function, progression after treatment, complications etc.). To help us better understand how patients with COPD progress we will collect data regarding the number of unscheduled healthcare consultations, defined as emergency primary care appointments, emergency department attendance at hospital and hospital admissions. This data will give us a better idea of how patients with COPD progress when receiving respiratory specialist care compared to 'usual care'.

How do I know my data is safe?

All data that could identify you will be removed while the data is still held within the NHS, and will be thoroughly checked before leaving the NHS database. Once this has been done, it will be securely transmitted and stored within a system that is both physically secure from intruders and protected by firewalls to prevent access from outsiders. Access to the data will be restricted to a list of specially trained individuals approved by the NHS. These security provisions have been approved by the hospital Information Governance Committee. This study has been reviewed and received favourable opinion by West Midlands – South Birmingham Research Ethics Committee

How do I know my data won't be misused?

Your data will only be used to answer specific research and service redesign questions that have been defined and approved by all members of the project's Governance Board. This Governance Board consists of members from all partner organisations, with additional patient and public health representatives. We have taken a number of measures to ensure compliance with national policy and legislation on patient privacy and data protection. At all times, your rights under the Data Protection Act will be upheld.

How will this benefit me?

The project will provide vital information regarding the quality of care patients with COPD receive in the primary care setting and will provide a comparison between respiratory specialist care and 'usual care'. This will allow us to evaluate if guideline based care leads to better health outcomes and quality of life in patients with COPD. We can then use this knowledge to improve clinical outcomes for patients with COPD and improve the coordination of care across services.