

TAKING CARE OF ASTHMA:

*A Patient & Public Involvement event to
improve the Asthma
Care Pathway*



January 2014

Patient and Public Involvement Asthma Event 13th January 2014

1. Background

As a part of Lewisham Clinical Commissioning Group's (LCCGs) *Improving Primary Care Programme*, there is an identified need to increase patient awareness, self-management and care of Asthma in Lewisham. A public event was delivered to engage patients, carers and family members in a discussion with Commissioners and Clinicians. We asked patients to provide details of their experience and views of using the current Asthma Care Pathway.

The event was designed to be partly informative and partly exploratory to achieve the following:

- Understand experiences of diagnoses and treatment options
- Understand who and how Asthma care is preferred to be received by participants
- Understand the levels of self-management undertaken before seeking assistance
- Explore the experiences of the current care pathway
- Identify opportunities to improve and/or amend the current pathway.

By involving patients and the public early, we are enabling them to influence and shape care pathways at the earliest possible stage – before decisions are made.

Widespread communication about the event was distributed through key partner organisations. Many of these organisations have direct service users who may have or care for patients with Asthma. Additional direct engagement took place within the community through existing community development workers who work with communities who are traditionally not represented in engagement activities. Transport was offered to those who needed/requested it. We provided transport to ensure we included vulnerable groups.

The event followed a format of 'brief' presentations by Clinical and Public Health leads in the Asthma care pathway, followed by round table discussions. Each table was hosted by a clinical member (GP, Nurse, Consultant), with facilitation/ note taking by a member of the Lewisham Clinical Commissioning Group.

This Feedback Report contains direct quotes from participants.

'The NHS belongs to the people. It is there to improve our health and well-being, supporting us to keep mentally and physically well, to get better when we are ill, and when we cannot fully recover, to stay as well as we can to the end of our lives' *The NHS Constitution*

2. Providing Patients with clear information and support to self-manage

Many patients came to the event feeling that using prescribed medication is the only way to manage their Asthma. During this discussion many patients reported how informative this event was – enabling them to change their approach to managing their condition:

- ‘A lot of this information I was not aware of so this session has been very informative
- Daughter has suffered with asthma for 30 years patient’s mother believes her daughters asthma is uncontrolled and would like to learn techniques such as resuscitation this will improve support to her daughter. She wants more information and does not have a computer, where can she find this information?
- Enjoyed talk very helpful’

3. How do you normally take care of your Asthma? Or what do you do to ensure you are managing your asthma?

Patients were able to explain how they manage their Asthma; with many giving examples of the limits they set before they seek additional clinical support. Patients said they:

- Manage bad days with inhalers and rest
- Recognise when it’s getting worse
- Take two puffs salbutamol wait 2 minutes and repeat and rest
- Patient cannot be around grass as the asthma gets worse, usually will visit the pharmacist if she cannot be remedied then she will go to the GP’.

4. Role of Clinical Staff

Included in this discussion, was a clear message to Commissioners on the importance of providing appropriate information in the places patients prefer. A few comments were made about GPs ability diagnose and refer appropriately:

- ‘On the maternity ward received nebuliser (1st diagnosis) I was not called up for a review and believe it would that it would have been helpful’.
- Dissatisfied with NHS so went private
- GP was not knowledgeable on Asthma

The role of GPs in caring for Asthma patients was raised very early on – at the presentation stage of this event. Participants raised a number of questions, which would suggest that assurance and confidence in their treatment was needed. Comments included:

- We see so many different GPs
- Do GPs need to be trained in Asthma – referring to management and diagnosis during crisis
- We need continuity of care – Named GP

4.1 Practice Nurses

During the table conversations there was strong support for the Practice Nurses in managing Asthma. Many Patients made positive references to their Practice Nurse, and there was shared agreement that Asthma Care should be provided by the Nurse:

- Practice nurse best to undertake annual review
- Get appropriate level of support from practice nurse and GP
- Continuity of care across the board communication between GP and practice nurse
- Would like practice nurse to specialise in asthma

5. Communicating about Asthma

Participants made some suggestions about communication and education needs that may provide some useful future activity as part of the wider Improving Primary Care Programme and the Self Care agenda. Participants suggested:

- Educate children in schools
- Improve on delivering knowledge updates on a regular basis
- Patient has not had an attack for a long time so is not aware of any support mechanisms in place
- Breathe Easy Group should be available for asthmatics

Based on these comments, we have learned that communication on Asthma Care reaches patients and carers during their 'active asthma' periods. The clear patient concern on communication is that patients want correct, updated information, ideally from Practice based staff.

6. Key Outcomes from the event

The Asthma event was very well received by participants. Many offered praise and thanked staff for the information and opportunity to learn about the Asthma Care Pathway – and discuss with others in a shared and supportive environment.

- Patients are keen to obtain Asthma Care from Practice Nurses
- Communication must target current and past Asthma service users
- Patients suggest we follow the Breathe Easy Support Group model as a self-care vehicle for Asthma.

7. Feedback to Patients

Participants will receive feedback on how their involvement has been used directly from the LCCG Commissioning Team, and also through the new LCCG pages in Lewisham Life.

8. Next steps for commissioners

- Public feedback gathered at this event will inform the new Asthma patient pathway.
- Patients will be invited to take an active role in the decision making process as the pathway is developed
- More events like this will take place in the coming months
- All patients participating in the event will receive a feedback report from us.
- The event will be promoted in Lewisham Life

9. Further information

If you would like to know more or would like to get involved please contact;

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