

## **Long Term Conditions**

### **Focus group discussions**

**2016**

The local NHS is looking again at the way it cares for people with long-term conditions – and is asking patients for help in getting services right. Growing numbers of people live with a long-term condition, and the NHS locally wants to find new ways of supporting this group of people to stay healthy, and stay in control of their condition.

Doctors feel that the health service is still too focused on providing a short-term response when someone's health is in crisis, rather than working with patients to stop them becoming acutely ill in the first place.

The current set-up is very varied - some groups of patients have easy access to staff and resources which can help them maintain good health, whereas others still have to rely on large numbers of hospital visits, or telling their story over and over again at numerous appointments with staff from different parts of the health and social care system.

Health leaders now want to find new ways of supporting people with long-term conditions, which gives all patients a better deal, and which makes the NHS more efficient. The term 'long-term conditions' includes diabetes, lung conditions such as COPD and asthma, musculo-skeletal conditions such as arthritis or osteoporosis, stroke, and coronary conditions such as heart failure or angina,

As part of the search for better services, patients with long-term conditions are being encouraged to tell NHS leaders about the care they receive now – both the good, and the not-so-good – and the care they would like to receive in future. The first stage of the process was a survey (carried out in 2015). Following on from the survey results, the local NHS are carrying out a series of face-to-face meetings between doctors and groups of patients, to explore in more detail how services can be improved.

Date:	04-02-16
Location:	COPD Breathe Easy group – Gosport Leisure Centre
Number of people taking part:	20
Facilitator:	Nick Brooks

Due to nature and size of group plus restricted time – focused on these 3 areas/objectives.

<b>Objective 4:</b>	<b>“Specialist input &amp; holistic care” – How do people feel we can balance a desire for specialist input, with a desire for holistic care?</b>
Starting point:	Particularly in the context of the frequency of living with multiple long term conditions – better to have multiple specialist for each condition or a more generalist/holistic overview of issues?
Prompts:	
<p>Feedback:</p> <p>Patients need consultants who can provide reassurance</p> <p>COPD takes in the need to see heart and respiratory specialist consultants.</p> <p>Several patients wanted to be able to have quick easy access to their own GP- but having your ‘Own GP’ is now very rare and most patients are under a group practice and could end up seeing anyone of the GPs.</p> <p>Having your own GP is now rare.</p> <p>Having access to specialist nurses was also seen as positive in the event where a patient can’t get a same day appointment with their GP, but could see a specialist nurse.</p> <p>They would like to see COPD patients treated in the same time frame as cancer.</p> <p>Some reported that GPs made access to specialists difficult, and explained that they were best placed to treat the condition, whilst at the same time the patient was seeing a specialist nurse, who is urging access to consultant. Others, it should be said, reported that their GP was well able to provide help and support, and to refer them on without question, when appropriate.</p> <p>Ideal scenario:  GP diagnosis- referral to specialist nurse and consultant  Specialist team keeps GP abreast of patient and their condition but oversees patient.</p>	

<b>Objective 5:</b>	<b>Patient education – what is available currently and what might they like to see in the future?</b>
Starting point:	People say they need more information... what do they mean by that...?
Prompts:	Format? Style? Frequency? Face-to-face?
<p>Feedback: Pulmonary rehab started approx. a year ago (2015)</p> <p><b>Key points:</b> The group reported mixed experiences in terms of the education they received to help them manage their condition.</p> <p>The time period between the point of diagnosis, and accessing education, varied considerably. Some GPs were said to take the time to go through the diagnosis and its implications, and then also arranged for the patient to spend time with a nurse to go through inhalers, overall condition etc.</p> <p>Others said that GPs gave them the diagnosis, but then they felt as if they were being sent away with little or no useful information, except for a leaflet/booklet to read through. This might then be the start of a lengthy wait for the start of the rehab programme – some participants reported this as being an extremely difficult time (emotionally).</p> <p>The time between diagnosis and rehab was felt to be crucial in terms of mentalhealth/wellbeing. Several participants talked about how a diagnosis had a negative impact on their mental health.</p> <p><b>Ideal scenario:</b> GP provides diagnosis and arranges for patient to see specialist respiratory nurse for 1:1 session to answer questions, walk through inhalers and how to use them, sign post them to local pulmonary rehab and support groups.</p> <p>Immediate referral to rehab course at point of diagnosis - this would help to prevent the condition getting worse and patient deteriorating further (particularly mental health).</p> <p>DVD/handy guide to asking right questions at different stages of the condition, info on the condition.</p> <p>Where specialist help and support is required (e.g. giving oxygen) ambulance crews are trained and patients don't have to teach them at a time when they have high anxiety/stress levels.</p>	

<b>Objective 6:</b>	<b>“Generally”..... talk us through what the current situation feels like, and what would change it to ‘good’ or indeed ‘great’?</b>
Starting point:	Not thinking about anything we’ve discussed already.... Draw up a wish list.... What would brilliant care look and feel like to you?
Prompts:	
<p>Feedback:</p> <p><b>Ideal scenario</b></p> <p>Same Day appointments with ‘own’ GP, as it was in the past.</p> <p>Use Trouper study ethos/process, wherein the patient was linked up with specialist staff/clinical staff who made the links between the patient, consultants and their own GP. They kept all parties informed and could arrange an appointment (speedily) with either a specialist nurse or consultant.</p> <p>Quick access via designated phone number to a specialist consultant /nurse – the group felt that a deterioration in their condition could be extremely frightening – causing anxiety and panic – making immediate access to specialist help particularly important.</p> <p>Provision of accessible CRIS/Specialist nurses in local community.</p> <p>Linking patient to other public organisations (via a signposter) to provide support and advice for financial support (for both patient and their carer).</p>	