1. Introduction and apologies for absence

Introductions were made and apologies noted as above.

2. Minutes from the previous steering group meeting 12.11.08

The previous meeting’s minutes were approved. It was noted that once the MCN’s website is online, all meeting minutes will be uploaded to the internet and made public.

3. Brief update on MCN development

Funding:
- A bid was made to the Scottish Executive; however, they were unwilling to give our MCN the same amount of funding as the other Scottish MCNs because we had already received some funding from ABPI.
- From the Scottish Government, we received £46,000 over two years for a supported self-care project. The MCN is currently discussing how this project should be done to produce a tangible product for patient information.
ACTION

- Chiesi Ltd has joined ABPI and is funding the MCN with £11,000 over two years. Unfortunately, because of the timing within the financial year, we were not able to get matching funds from NHS Lothian. The MCN is working with ABPI on how to spend these extra funds. Some options include the creation of the website, launch events for the COPD Guidelines and backfill pay for training.

Quality assurance group:
- The next meeting of the quality assurance action sub group will take place on Thursday 19 March 2009.
- NHSQIS are developing clinical indicators for COPD. Jo Pentland and Prof Bill MacNee are on this group. They have a draft nearing completion to be discussed at their next meeting on the 17 March 2009. They are hoping for a final document by early summer.
- The MCN would like to encourage practices to use Campbell Software because it would be helpful in gathering information.
- The MCN needs to have quality indicators in place by the end of its second year, so we are currently ahead of schedule.

Oxygen therapy:
- The next meeting of the oxygen therapy action sub group will take place on Thursday 16 April 2009.
- Prof MacNee has created a draft local guideline and the group will discuss this at the meeting in April. The goal is to produce a one to two page practical document.
- West Lothian has policies on oxygen therapy but the rest of Lothian does not. Issues regarding referral procedures, treatment options and smoking need to be addressed.

Links:
NH explained that because there are already groups in place for smoking cessation and palliative care, we have deliberately not created action groups for these areas; instead we have created and maintained links with the current groups.

Smoking cessation:
- Helena Connelly is the smoking cessation manager for Lothian. There are two smoking cessation workers in place in every CHP in addition to one person each in the Royal Infirmary of Edinburgh and the Western General Hospital. They are trying to get someone into the Astley Ainslie Hospital as well.
- Everyone has access to refer to smoking cessation and patients can refer themselves.
- Within the context of the MCN, it was felt the most productive connection for smoking cessation is with the pulmonary rehabilitation teams.
- The Smokeline website will tell patients where to find their nearest stop smoking service and is being included in the COPD guidelines.
- Lesley Duff explained that this information is kept on a register
and patients are contacted at three months and 12 months. An audit a few years ago showed that more COPD patients were still smoking than not smoking.

Palliative care:
- There is a separate Palliative Care MCN. AB and NH have met with the manager, David Oxenham and attended the workshop on the 28th of January 2009.
- Palliative care within the community is changing. There are more patients on the palliative care register who do not have cancer but have other conditions such as heart disease, dementia and COPD. For example, NH’s palliative care register at his practice has only three cancer patients and 15 patients with other conditions.

4. Focus on pulmonary rehabilitation – Jo Pentland
- The pulmonary rehabilitation service in Lothian has changed a lot over the years. In the beginning, the Royal Infirmary of Edinburgh provided the only pulmonary rehabilitation service for patients. As a result, there was a long waiting list, classes were only available once a week and patients without a Royal Infirmary of Edinburgh or Western General Hospital consultant received no pulmonary rehabilitation. Now, with the help of Chest, Heart and Stroke Scotland, Long Term Conditions funding by CHPs, services are in place in each CHP across Lothian and services have improved. The classes are also more structured than they have been in the past.
- There is networking between all sites, the Royal Infirmary of Edinburgh service is able to provide twice-weekly classes, there is a bigger sample size for research and more patients are able to be offered pulmonary rehabilitation.
- Patient-led goals are very important in motivating patients to attend classes.

Royal Infirmary of Edinburgh:
- One rolling programme
- Twice weekly for six weeks
- On final visit, outcome measures are repeated
- No follow-up programme
- Information provided about local gym use
- The classes at the Royal Infirmary of Edinburgh involve cardiovascular training, strength training and education sessions.

Edinburgh community service:
- Started in September 2007 with funding from Chest, Heart and Stroke Scotland until March 2009, but this funding has now been extended for an additional year.
- There are six programmes, three at Leith Community Treatment Centre, two at Sighthill and one at Gracemount. They are all rolling programmes.
- There is a follow up for one year at three monthly intervals in
ACTION

which they re-evaluate walking tests, the Chronic Respiratory Disease Questionnaire (evaluates symptoms of breathlessness, control physical and mental well-being), smoking history and record any exacerbation and hospital admission information.

- There is a maintenance pilot programme consisting of a once weekly session at Leith Victoria Swim Centre for ten weeks. This will be evaluated upon completion.

East and Midlothian:

- Funding started in April 2008 and the first programme began in June 2008. The Long-Term Conditions group has extended this funding until 2010.
- Four twice-weekly six-week programmes are offered at five possible venues throughout East and Midlothian.
- These are not rolling programmes and are secondary to staffing.
- Ideally will have 12 patients in each group.
- The follow-up consists of the Chronic Respiratory Disease Questionnaire and a phone call at three months.
- There is no formal maintenance programme.

West Lothian:

- Started in October 2007 and was initially funded for two years, but the West Lothian CHCP will now provide continual funding.
- There are two programmes, one in Bathgate and another in Broxburn. They run an eight week programme with twice-weekly sessions.
- In March 2009, staffing will increase and there will be four programmes available.
- The follow-up consists of postal questionnaires at three and 12 months and an assessment of activity levels and admissions and exacerbations. There is a return appointment at six months to repeat the initial assessment.
- There is no maintenance programme.
- Shena Brown explained the last week of rehabilitation takes place in the local gym. She has found this has helped patients feel much more comfortable in a gym setting and makes it more likely they will continue to go to the gym on their own after they have completed the programme.

- The pulmonary rehabilitation action sub group is working to ensure uniformity in the referral process. They are doing this by reviewing and updating inclusion criteria, the referral pathway and paperwork and performing an audit of the service.
- Once the referral criteria and pathway have been clarified, the service will be more demanding of the referrals and reserve the right to refuse them if the forms are not completed correctly.
- All clinics should have correct information on how to refer to pulmonary rehabilitation. The service is looking at a paper
ACTION

form based on Sci Gateway. JP will e-mail this information to Dr Alistair Innes and Dr Peter Reid.

The audit:

- There is £1500 available from Boheringer Ingelheim to audit the current pulmonary rehabilitation service. This will be a retrospective audit. The possible outcomes to be investigated include:
  - Incremental shuttle walking tests
  - Endurance shuttle walking tests
  - Chronic respiratory disease questionnaires
  - Follow-up systems
  - Content of each pulmonary rehabilitation class
  - Hospital admissions
- Brian Montgomery stressed the importance of gaining hard evidence to better justify additional and continued funding.
- Pulmonary rehabilitation is a very cost effective treatment. Figures in Leith show a 50% increase in exercise tolerance. The audit must be careful when choosing quality indicators because being able to walk an additional 25 meters might be a small improvement for one patient, but a huge improvement for another.
- There is the initial problem of getting pulmonary rehabilitation services to those who have never had it but who would benefit. We also need to figure out how much rehabilitation is necessary after the programme is finished.
- NH thanked JP for her presentation and congratulated the pulmonary rehabilitation service on the changes and improvements made.

5. Focus on supported self-care – Dr Ninian Hewitt

- There are many terms relating to self-care so NH clarified the terms being used.
- Supported self-care is how the patient copes with their conditions within their daily lives with the support of the medical community.
- Anticipatory care plan – This is a term only used by professionals to other professionals when discussing the future care of a patient.
- Self-management plan – This is a term for patients. It is the information they hold to take care of themselves with input from their GP. The supported self-care group has developed a self-management plan for COPD and this will hopefully be in use soon.
- The group has also developed a generic template of a service map that can be CHP specific so everyone knows where to go for each service.
- The MCN has been given £46,000 over two years by the Scottish Government for a supported self-care project. The group is discussing some options for this project and it is important it has definite outcomes. There is good evidence that when patients are given information for self-management, they like this and feel better, but it does not reduce their visits
to the GP or hospital admissions, so the hoped for cost saving benefit is not there.

- BM says supported self-care is a major initiative for the long-term conditions collaborative and both groups need to work together to avoid differing answers to supported self-care questions. There are some resources available through the long-term conditions collaborative and BM would be happy to discuss this with AB and NH. He also suggests contacting Rachel Hardie, a consultant in the public health department.

**AB**

6. **Focus on spirometry and training**

- Andy Robson audited two and a half years of referrals into the respiratory function service at the Western General Hospital and the Royal Infirmary of Edinburgh and found the results to be disturbing. 75% of those referred did not have COPD. 50% of those referred for a repeat test did not have COPD which means they had been incorrectly labelled as having COPD and their files never updated or changed.

- The respiratory function service needs to be used more appropriately. The MCN submitted a bid for a diagnostic spirometry service asking for £100,000 start-up funds and £70,000 per year. This bid was not successful and now the group has agreed to try to restructure the current service. There are currently 2000 referral slots available per year for East and Midlothian and the group would like these to become purely diagnostic.

- NH wrote to the Lothian Local Medical Committee asking for their support of the restructure. They are meeting next week and if they agree, the project can begin.

- AI made particular note of his dismay that proper diagnosis is not supported by NHS Lothian. The group will submit the bid again next year and try to clarify the various stages it must go through to be accepted. The CHPs should also be informed as to how badly the service is being used. BM suggested having a clear vision for the respiratory services in Lothian and the future direction of the MCN. If we are able to clearly show NHS Lothian how delivering that vision will help them achieve their targets, the bid will be more successful next time.

- Spirometry training is an important issue and classes have been struggling to get enough students to justify their cost. Many nurses are not supported by their GPs to attend these courses.

- West Lothian has submitted bids for one healthcare assistant and one respiratory physiologist. Funding is approved for the physiologist; however, the post is with Human Resources for grading prior to advertisement.

7. **COPD guidelines**

- The COPD guidelines are now in their final form and NH thanked everyone who contributed.

- There will be a rolling launch in each of the CHPs with help from ABPI. NH will present the guidelines to GPs and nurses and there will also be an educational element, most likely regarding spirometry.
ACTION

- Once we receive copyright permission from GOLD for use of the treatment charts, we will begin official dissemination of the guidelines.
- They will be disseminated in the following ways:
  - Paper
  - e-mail
  - intranet
  - internet
  - laminated treatment charts
  - RefHelp

8. Any other business
National Respiratory MCNs – Steering Group:
- This is a group for all respiratory MCNs throughout Scotland. Their most recent meeting took place on 5 February 2009 and the minutes from that meeting will be distributed with these minutes. The National Respiratory MCN Steering Group is writing a Scottish strategy, AB is working with them on this.  
  KT  
  AB

Long-Term Conditions Collaborative:
- They are currently advertising for a lead clinician; anyone from a clinical background to do up to two sessions per week.

National COPD Audit:
- The 2008 audit is now available on their website. Dr Peter Reid said this was a powerful audit with 98% of acute hospital trusts and divisions in the UK participating.
- Some of the results for the WGH showed:
  - Patients have a median of 50 pack years v the National average of 40.
  - Average length of stay in hospital was five days; this is the same as the National average.
  - Readmission rates were high.

Chest, Heart and Stroke Scotland:
- Nicola Cotter announced that CHSS has funding for a respiratory coordinator. They would like this post to look at service development and help with training and patient information. CHSS will be developing the job description soon.

9. Date for next meeting
TBC