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**RQIA Review of Community Respiratory Services
in Northern Ireland**

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Assurance, Challenge and Improvement in Health and Social Care

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The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on our website at www.rqia.org.uk.

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Executive Summary

Respiratory disease refers to a wide range of illnesses that can affect the upper or lower respiratory tracts, either acutely or chronically. People with respiratory diseases often require the expertise of a range of health and social care professionals who have specialised skills in the field of respiratory care. This includes prevention, assessment, diagnosis, treatment, rehabilitation and palliative care. Community respiratory services are designed to provide services close to people's homes or in the home. They generally cover disease areas such as Chronic Obstructive Pulmonary Disease (COPD), bronchiectasis, idiopathic pulmonary fibrosis and provision of Non Invasive Ventilation (NIV) services to those with respiratory and some neurological conditions.

In Northern Ireland in 2012/13, using only the primary diagnoses of bronchitis, emphysema and other COPD (as primary and first secondary diagnosis), there were 10,133 admissions to acute hospitals, using 69,099 bed days and an average length of stay of 6.8 days¹.

The Integrated Care Partnerships (ICPs) are considering respiratory services as part of the Transforming Your Care (TYC) model and the work of the ICPs and commissioning processes were highlighted as important drivers which affect the current and future effectiveness of the specialist community respiratory services.

The review team was impressed with the community respiratory service across Northern Ireland. The community based system, working closely with primary care and reaching into secondary care, was considered to be an excellent model. This Northern Ireland model is a patient-centred service, providing a potentially comprehensive response across the whole disease spectrum, from newly diagnosed to end of life care, reflecting the TYC.

The review team identified significant gaps in specialist areas for people with non-invasive ventilation (NIV), Interstitial Lung Disease (ILD) and Obstructive Sleep Apnoea Hypopnea Syndrome (OSAHS). A combined regional and local approach is required for NIV and ILD.

Generally respiratory teams across the five HSC trusts are well integrated and have good insight into how their service is operating. Staff are responsive, knowledgeable and have identified gaps and the need for improvements in their services. They have produced solutions to address these gaps. General practitioners (GPs) are supportive and appreciative of the work of the community respiratory teams in providing patient care.

The review team made recommendations in relation to development of equitable service provision for patients across all trust areas.

¹ [Revised Service Framework for Respiratory Health and Wellbeing Consultation](#). Appendix 3. DHSSPS, January 2015.

These recommendations relate to commissioning, in terms of staffing provision and sustainability of funding. Recommendations are made about availability of out of hours services, pulmonary rehabilitation and bronchiectasis. New services, including oxygen services, should be sustainably funded. There were individual recommendations made for each of the five trusts for specific issues.

Groups of service users spoke highly about the staff, as well as the community respiratory services they have received. They were well informed about how and when they could contact community respiratory services. In general, the links with the voluntary sector are good.

The review team has made a number of recommendations for the HSC Board and trusts to improve specialist community respiratory services.

Section 1 Introduction

1.1 Background

RQIA accepted this commissioned review from the Department of Health Social Services and Public Safety (DHSSPS) for inclusion in its three year review programme 2012–2015.

Respiratory disease refers to a wide range of conditions that can affect the upper or lower respiratory tracts, either acutely or chronically. People with respiratory diseases often require the expertise of a range of health and social care professionals, who have specialised skills in the field of respiratory care. This includes prevention, assessment, diagnosis, treatment, chronic disease management, rehabilitation and palliative care.

Some of the most common respiratory diseases considered as part of this review are:

- Chronic obstructive pulmonary disease (COPD) – a range of lung diseases including chronic bronchitis, emphysema and chronic obstructive airways disease. One of the most common respiratory diseases in the UK usually affecting people over the age of 35, although diagnosis may not be confirmed until later in life.
- Obstructive sleep apnoea hypopnoea syndrome (OSAHS) – a condition, in which the upper airway collapses and briefly obstructs breathing, leading to disrupted sleep patterns. It can result in excessive daytime sleepiness which is a major factor for road traffic accidents. It is likely to be underdiagnosed due to lack of awareness of the condition.
- Bronchiectasis – a condition in which there is permanent dilation of the bronchi, leading to inflammation and infection. Likely to be under-reported with the incidence increasing with age.
- Interstitial lung disease (ILD) – a classification that includes over 200 disorders affecting the functional part of the lung. All present with increasing shortness of breath and widespread shadowing on a chest x-ray. Three ILDs contribute the largest impact on the population and the health service; idiopathic pulmonary fibrosis (IPF); sarcoidosis; extrinsic allergic alveolitis (EAA), now known as Hypersensitivity Pneumonitis (HP).

1.2 Context for the Review

Northern Ireland has a population of approximately 1.8 million, with a growing and ageing population, suffering from poorer health. Respiratory disease is the third most common cause of death in Northern Ireland, after cancer and cardiovascular disease.²

Death rates from respiratory disease in the UK and Ireland rank among the worst in Europe. Using the World Health Organisation International Classification of Disease (ICD10) system, there were 2,023 deaths from respiratory diseases in Northern Ireland in 2012, accounting for 14 per cent of the total deaths that year³. (The ICD10 respiratory disease category includes lower respiratory tract infections, chronic lower respiratory diseases such as COPD, asthma, lung disease due to external agents, and other diseases affecting the interstitium. It does not include tuberculosis, pulmonary hypertension, sleep apnoea, lung cancer and congenital diseases.)

The majority of deaths from respiratory disease in Northern Ireland occur in the elderly population. As people are living longer, and are surviving conditions such as myocardial infarction and cancer, the prevalence of respiratory disease and number of people dying from respiratory causes is expected to rise. This has implications for service provision, including an increased need for social and emotional support, support in the home and community, and increased palliative care requirements, especially for those with chronic respiratory diseases.

TYC⁴ sets out an overarching road map for change in the provision of health and social care services in Northern Ireland. It includes 11 reasons for change. Four of the 11 that are very pertinent to this review are:

- the need to be better at preventing ill health
- the importance of patient centred care
- increasing demand on all programmes of care
- the current inequalities in the health of the population.

TYC also suggests that people are best cared for as close to home as possible. The TYC Omnibus survey reports that 81 per cent of people surveyed said that more health and social care services should be delivered in GP surgeries, local centres and in people's homes. The survey highlighted dissatisfaction with the accessibility of services and with the quality of services for older people.

² [Service Framework for Respiratory Health and Wellbeing](#) DHSSPS, 2010.

³ [Revised Service Framework for Respiratory Health and Wellbeing Consultation](#). Section 3. DHSSPS, January 2015.

⁴ [Transforming Your Care](#), A Review of Health and Social Care in Northern Ireland. HSC Board 2011

Moving Care into the Community

TYC outlines how care should be provided at home, or as close to home as possible. Some services currently provided in acute hospitals could be provided in the community or in people's own homes, making them more accessible. Going forward, TYC stated that the health and social care system should provide local services for local people, but safe, sustainable and accessible services for populations. As a result, there has been a significant amount of work undertaken to plan and move healthcare from acute hospitals to community settings.

Reducing the Length of Stay in Acute Hospitals

In Northern Ireland in 2012-13, using only the primary diagnoses of bronchitis, emphysema and other COPD (as primary and first secondary diagnosis), there were 10,133 admissions, using 69,099 bed days and an average length of stay of 6.8 days⁵. Acute hospitals are now attempting to reduce the length of stay for patients who do not need to be in hospital and to prioritise care for patients who are more acutely ill. Increasing demand on acute beds means hospitals have to improve their discharge arrangements, with community teams providing an increased level of care outside the acute ward. Specialist teams may provide care to people in their own homes to effect an early discharge or prevent acute hospital admissions in the first place.

Service Frameworks

Some of the most prevalent long term conditions are addressed by service frameworks issued by the DHSSPS. Among these are the cardiovascular, respiratory, cancer and older people service frameworks. These frameworks are designed to promote and secure delivery along the whole care pathway, from prevention, diagnosis, treatment and rehabilitation, to end of life care.

In 2010, the first Service Framework for Respiratory Health and Wellbeing⁶ was produced and, at the end of 2014, a revised service framework for Respiratory Health and Wellbeing was published for public consultation. The revised framework included a wide range of respiratory conditions. With respect to services provided in people's own homes, the following specific areas included in the respiratory framework are relevant:

- COPD, including palliative care
- Bronchiectasis
- ILD, including palliative care
- OSAHS in adults

Services relating to a number of these diseases include:

- Oxygen therapy
- Long term ventilation in adults

⁵ [Revised Service Framework for Respiratory Health and Wellbeing Consultation](#). Appendix 3. DHSSPS, January 2015.

⁶ [Service Framework for Respiratory Health and Wellbeing](#). DHSSPS, 2010.

For these specific conditions, there are many standards and guidelines that informed the work of this review, including those produced by The National Institute for Health and Care Excellence (NICE), the British Thoracic Society (BTS), the DHSSPS, the Scottish Intercollegiate Guidelines Network (SIGN) and the Global Initiative for Chronic Obstructive Lung Disease (GOLD).

Community Respiratory Services

Community respiratory services are designed to provide services close to people's homes or in the home. They generally cover disease areas such as COPD, bronchiectasis, idiopathic pulmonary fibrosis and provision of Non Invasive Ventilation (NIV) services to those with respiratory and some neurological conditions.

Community respiratory teams should offer access to a range of prevention, social and emotional support services; enhanced supportive self-management; admission avoidance; exacerbation management; early supported discharge; pulmonary rehabilitation; oxygen services and palliative care. They should support primary care staff and work closely with all primary, secondary and community care staff to ensure smooth provision of services.

Many of these services are provided in the patients' homes. Where someone is able to attend a community outpatient clinic, this is appropriate, to allow cost effective provision of services, and closer accessibility to patients, especially in rural areas.

Service development proposals are currently being planned to include extended opening hours during week days and Saturday and Sunday availability.

Community and Specialist Teams

An initial scoping exercise across the five HSC trusts identified a wide range of multidisciplinary teams. All HSC trusts have community respiratory teams, which include respiratory nurses and physiotherapists, although other allied health professionals may be involved, for example, occupational therapists and dieticians. Some trusts also have psychologists as team members.

Delegated Tasks

Some healthcare tasks can be delegated and others cannot. The most common example of delegation would be of a specific task from a registered nurse to a Health Care Assistant (HCA) or to a member of the patients' family. Another example is where a technical assistant within a respiratory team can deliver pulmonary rehabilitation exercises in a patient's own home which have been devised by a physiotherapist. However, there is variation in the practice of delegation. This review has assessed current practice in this area.

Assurance

RQIA's Corporate Strategy 2015-2018⁷ describes three key stakeholder outcomes: Is care safe? Is care effective? Is care compassionate? This review will present the findings across the five HSC trusts that evidence that care is meeting these outcomes. Quality 2020⁸ defines effectiveness as the degree to which each person receives the right care, at the right time in the right place, with the best outcome. This review has assessed community respiratory teams to ensure the right people are delivering the right care, at the right time in the right place, with the best outcome, including services provided for people in their own homes.

1.3 Terms of Reference

The review:

- Describes the current arrangements for the provision of community respiratory services, to include services in people's own homes across the five HSC trusts.
- Reviews the governance arrangements which ensure the safe delivery of community respiratory services.
- Assesses the arrangements in place that ensure specialist services are effective, according to best practice, recognised standards, guidance and frameworks.
- Reviews the coordination and integration between specialist community teams and the links with primary care and acute services.
- Describes the views of the service users and their carers.
- Reports on the findings, highlights good practice and makes specific recommendations for improvements.

1.4 Exclusions

Circulars, guidance, standards, reviews and reports which arise during the course of this review are not considered but will be highlighted for consideration in the future.

It was agreed to exclude children from the review, as these services are provided differently.

Respiratory conditions were chosen because they represented the core of the work in the respiratory teams and can require and receive input at home at certain stages of illness.

Cystic fibrosis was excluded, as it is managed by a separate specialist team.

⁷ [RQIA Corporate Strategy 2015-18](#)

⁸ [Quality 2020. DHSSPS](#)

1.5 Review Methodology

1. A broad scoping of available, relevant information was undertaken, to include service frameworks, standards and guidelines.
2. Initial meetings were held with each HSC trust (except for the Northern Ireland Ambulance Service HSC Trust (NIAS)), to establish an overview of their structures and details of the teams providing community respiratory services, including services in people's own homes.
3. A baseline questionnaire was completed by the trusts to provide the review team with relevant information regarding community respiratory services.
4. The review team met with staff from community respiratory teams and this was followed up by meetings with trusts' senior managers.
5. Service users from across Northern Ireland were asked for their views of the community respiratory service. Interviews were conducted with members of the Northern Ireland Chest Heart and Stroke groups and the British Lung Foundation's Breathe Easy groups.
6. In addition to the trusts, information on the structures, commissioning and links with primary care were sought from the following:
 - GPs (Integrated Care Partnership (ICP) leads)
 - Commissioners (HSC Board)
 - Regional Respiratory Lead (Public Health Agency (PHA))
 - Long Term Condition Alliance Northern Ireland (LTCANI)

Section 2 Findings from the Review

The findings in this section are reported in two parts.

- Service Users' Feedback
- Health and Social Care Trust and ICP Findings

2.1 Service Users' Feedback

At the commencement of the review the LTCANI was very informative in providing information and contacts relating to the possible conditions that could have been included. LTCANI was able to signpost suitable organisations, including groups of service users with recent experiences who could provide meaningful feedback on community respiratory services.

Four service user groups were able to participate in this review. Two Breathe Easy groups from the British Lung Foundation from Causeway and Fermanagh and South Tyrone; and two groups from Northern Ireland Chest, Heart and Stroke, one in Belfast and one in Lisburn. Groups included a range of service users; such as a small number of members who came together for the purpose of providing feedback, a pulmonary rehabilitation class; a group meeting and a group that had completed the self-management programme with Northern Ireland Chest Heart and Stroke. The numbers participating ranged from three people to over 40. The groups contained people who had experience of the community respiratory service, in particular pulmonary rehabilitation, COPD, bronchiectasis, chronic asthma, oxygen services and telehealth.

Each group was asked the following questions:

1. How would you describe the Community Respiratory Services?
2. If you had a problem, did you know who to contact?
3. Was access to the service available in a timely manner?
4. Did you feel you had been listened to?
5. What other services are you aware of?
6. Did you know of Pulmonary Rehabilitation?
7. Do you feel the service is compassionate?

All groups spoke in positive terms about community respiratory services. When asked, no one wished to report any negative comments about the services; only one group reported that it thought there should be more staff in the Fermanagh area. Participants wished to know more about the services. Signposting of available services was thought to be lacking, such as home oxygen, information on oxygen cylinders, pulmonary rehabilitation and maintenance classes.

Everyone believed they knew who to contact in the event of needing help should they become ill. Most responses indicated this would be their GP or the out of hours services. A few people knew they could call the community

respiratory service. They not only knew they could call directly, but some attending the Lisburn meeting carried a business card with the contact telephone number of their community respiratory team and understood also that this was not to be used during the out of hours period.

No one complained about the timeliness of the services received. People were aware that the more urgent your need, the faster you would be seen by the team. The patients had experiences of requesting assistance from their community respiratory teams and receiving a home visit the same day. Primary care services had reserved emergency appointments, available on the day, for people to request via telephone as soon as a general practice opened. However, there was some frustration that when people knew they were becoming ill and needed to have an appointment in the next day or two, that booking systems could not accommodate this. The only options were to call the following day for an urgent appointment or make a routine appointment, usually scheduled for the next one to two weeks.

People present in each meeting knew of the range of services available. However, not all attenders were informed to the same degree. Information seemed to be provided by the voluntary sector usually. Not all services are available in all trusts. The people who took part in this review were aware of the services provided by their particular trust but did not know if other trusts provided similar services for their patients. Over half of those attending knew of pulmonary rehabilitation.

Service users were not as aware of maintenance classes and no one knew if their trust allowed self-referral back to rehabilitation after 12 months. Maintenance classes were described as a “lifeline” by some and “vital” by others. From the numerous personal experiences described, most felt “it really does help.”

Weekly access to members of the community respiratory team during maintenance classes was appreciated by patients (in Lisburn and Causeway). Service users said that the staff gave them the confidence to regain their independence, which was invaluable to them. People spoke very movingly about being able to leave their homes or recommencing activities they had thought were too physically demanding for respiratory patients. Having weekly access to the community respiratory service also allowed patients to ask staff questions, and to have diagnostic tests submitted faster and more conveniently.

All groups agreed that staff from their community respiratory service were compassionate and caring. They knew their team well and praised the staff highly. It was obvious that those present had built meaningful relationships with their local teams and relied on the staff. Groups also appreciated the work of the voluntary sector organisations which supported and assisted people; namely Northern Ireland Chest Heart and Stroke and the Breath Easy groups of the British Lung Foundation.

2.2 Community Respiratory Staffing Levels

The five HSC trusts reported their existing staffing levels as part of a profiling questionnaire submitted to RQIA in advance of meeting the review team. During meetings with the review team, ICP and commissioning representatives confirmed new staff and the current funding arrangements.

Table 1 shows the number of people with COPD registered with GPs in 2014/15. The number of staff in post at April 2015 is shown, as well as the number of new community respiratory staff funded but not yet in post. The number of whole time equivalent (WTE) staff available per 1,000 people has been calculated, taking new staffing provision into account. This shows the number of WTEs varying from 2.2 in the Southern HSC Trust to 2.9 in the Belfast HSC Trust. These staffing levels do not enable the provision of the same range of services and this is discussed in each individual trust section following.

Table 1: Staffing levels per 1,000 people with COPD for five HSC trusts

Trust	Number of People with COPD registered 2014/15	Number of existing CRS staff March '15	Number of existing staff per 1,000 people with COPD	Number of new CRS staff funded but not yet in post ¹	Funding arrangements	No of CRS total staff to be available per 1,000 people with COPD
Belfast	9,668	16.3	1.7	11.5	Recurrent	2.9
Northern	8,775	12.7 ²	1.4	8.8	Non-recurrent. 1 year funding.	2.4
South Eastern	5,209	12.0	2.3	2.0	(HOSAR, 2 years funding)	2.7
Southern	6,564	11.9	1.8	2.4	Recurrent (HOSAR bid to be submitted)	2.2
Western	6,772	19	2.8	0	HOSAR funding 1year	2.8 ³

1 New staff for HOSAR and increased numbers to CRS, not in post as of March 2015

2 Includes HOSAR staff non-recurrently funded for 2 years

3 Western HSC Trust figures only include physiotherapy input into pulmonary rehabilitation in the Southern sector

All figures exclude administration staff.

All grades have been included in the WTE totals.

Non-recurrent funding will be discussed further.

2.3 Belfast HSC Trust

Workforce

The trust has 16.3 WTE in the community respiratory teams which will increase by an additional 11.5 WTE, recurrently funded. This planned increase will provide a more fully comprehensive service for the people in the Belfast area.

Community Respiratory Service, Structures and Teams

The community respiratory service has a multidisciplinary team covering the Belfast HSC Trust, accommodated in two offices with access to GPs with a special interest in respiratory medicine. This team has existed within the service for over 10 years. The role of Assistant Physiotherapy Manager for Respiratory and Specialist Services (currently vacant) is to work alongside nurse management and assists in providing professional leadership for the physiotherapy staff working within the community respiratory team. The team wishes to increase occupational therapy and dietetics inputs.

The review team was informed that all professionals are being managed by an appropriate manager from the same discipline. A physiotherapist from the acute sector rotates every year into the community and this was seen as a valuable opportunity for learning and development.

The review team met a wide range of professionals which included consultants, GPs, nurses, physiotherapists and the voluntary sector (Northern Ireland Chest Heart and Stroke Association). The review team found community respiratory team members to be well informed and knowledgeable about what constitutes a good service. This was considered to be a well-integrated team, linking with other teams across the trust.

Teams hold weekly multidisciplinary meetings which review referrals and then assign cases to the most appropriate member. Patients who are well are not discharged completely. They remain on the caseload, although inactive, and can make contact again quickly, should their condition deteriorate. Teams follow patients through to palliative care, as necessary, which is delivered by the community respiratory service, with help from the district nursing team for end of life care. During the out of hours period, the community respiratory service is supported by a 24 hour community nursing team.

The team has recently received £646,000 additional permanent funding. This will allow a fully integrated service to be provided for people with COPD. Additionally, an integrated bronchiectasis service will be available with nursing and physiotherapy input across the trust area. A new clinical psychologist is joining the team to treat patients and provide training to staff.

GPs are funded by the HSC Board to complete risk stratification work using the HSC Board data collection tool that will identify the 20 per cent of patients most at risk of a hospital admission or re-admission. The respiratory team is seeking to work more closely with GPs and practice nurses.

The community respiratory service looks after patients with respiratory conditions requiring NIV but not patients with other neurological conditions. There are no patients with a tracheostomy currently being looked after. There are between three and five ventilated patients, which places a considerable demand on the team. The service is not funded to care for any patients with neurological conditions.

The community respiratory service optimises use of their time and capacity by seeing people in the most suitable settings. Appropriately, some patients are seen in their own home, especially for first assessments which were considered to be much more holistic when set in the patients' own homes. Other patients are routinely seen in outpatient clinics. The team describes its approach as being proactive, not reactive.

People with COPD are identified on their first admission to hospital as this is seen as a significant event and referred to the community team for early follow-up at home. The team uses this opportunity to work with patients to try to prevent a second admission. The review team considered this to be a positive and progressive approach. A COPD discharge bundle has been introduced and the review team was informed this is working well. This care bundle helps to ensure all aspects of care are addressed. It is normally instigated by acute teams in the hospital and continued in the community. A bronchiectasis care bundle has also been piloted on one site. Some patients have been taught to self-administer their own intravenous medications, so avoiding the need for daily visits by nursing staff.

Belfast HSC Trust reported that the home-based pulmonary rehabilitation programme has the delegated task of supervising the patient whilst they continue the exercise programme. These programmes are set by the band six or band seven respiratory specialist physiotherapists. The physiotherapist assistant undertakes this task in the patient's home if the patient is unable to attend the group pulmonary rehabilitation programme within the Health and Wellbeing Centres. They will visit the patient twice per week for a period of six weeks.

Communication

The electronic care record (ECR) has allowed the community respiratory service to access patient records, but this is limited to read only access. One of the recommendations from the Respiratory Unscheduled Care Work Stream, chaired by the Chief Medical Officer and the Chief Nursing Officer, was to support respiratory teams accessing and amending patient records, thereby improving the use of ECR even further.

On discharge from an acute setting, information provided by a respiratory nurse specialist allowed sensitive, often palliative care information to be followed up by the community respiratory team. The review team was informed that when patients with severe COPD were discharged from hospital, information provided by a respiratory nurse specialist was perhaps more useful than a discharge letter, because the nurse knew the patient and their condition better than the junior doctor who prepared the discharge letter.

Patient letters from acute care are uploaded to the ECR, but community letters are not.

The review team was told that the community respiratory service receives good support from acute respiratory consultants and GPs. In the future the ICP is hoping to have clusters of general practices which will have an identified link respiratory nurse specialist. In the community, there are reports of practice nurses without specialist training or education, working with patients with COPD. Plans for increased training and links between general practices and specialist services should lead to improvements in this area.

Training and Education

Cognitive behavioural therapy (CBT), Sage and Thyme (communication training), End of Life Care, palliative and advance care planning training had been provided for community respiratory teams. Separate meetings with acute consultants and general practitioners with special interests take place weekly to discuss patients and support learning. The team reported good training links with specialist palliative care, Marie Curie nursing services and hospices.

Palliative Care

Patients with COPD are supported in their choice of whether to remain at home or receive palliative care in hospital. Support is provided for members of community respiratory teams, in order to deal with the stress associated with difficult palliative care issues. The complexity of patients' needs with respiratory disease is a source of pressure and stress for families and for members of community respiratory teams. The respiratory teams now manage very sick patients, post-acute discharge, with many symptoms affecting quality of life and with increased anxiety and depression. This has also a huge emotional impact on the team and individuals within the team. Appropriate supports have been implemented and a need for further training has been identified.

The community respiratory service reported having good access to hospices with consultant to consultant referral required for all patients. A fax referral to the hospice palliative team means that patients are usually assessed within an appropriate timeframe.

Pulmonary Rehabilitation

Community respiratory teams provide a rolling programme of pulmonary rehabilitation classes in a variety of locations, with referrals accepted from acute services, GPs and the members of the multidisciplinary respiratory team. Patients can also be re-referred to pulmonary rehabilitation. Waiting times vary between four to six weeks depending on the sector. The uptake could be improved as currently approximately 21 per cent of referrals fail to attend. However, the number of people completing the two sessions per week for the full six week period is high. The teams felt that GPs could better inform patients about the benefits of pulmonary rehabilitation to improve uptake. Primary care staff could also be more efficient at referring patients with bronchiectasis and ILD. The bronchiectasis specialist physiotherapist

and nurse currently provide specific bronchiectasis rehabilitation in the acute setting which will be rolled out to the community as a result of the new investment. Home rehabilitation and maintenance is provided for people who are house-bound or who lack confidence to attend groups. The team also follows up on those who drop out, refuse to start or need some encouragement to commence the routine programme. Transportation costs are a barrier to some patients attending pulmonary rehabilitation. The cost of the journey twice a week for six weeks and the time taken are the main factors. Classes need to be as geographically accessible as possible.

The new funding will allow a comprehensive service to be appropriately provided, where needed, into the evenings.

Obstructive Sleep Apnoea Hypopnea Syndrome (OSAHS) Services

The sleep service is under pressure with waiting times of 18 months being reported for just one part of the pathway. There are staff vacancies and an increasing level of demand for the service. The review team was concerned about the very long waiting times in different parts of this service and the implication for patients and public safety. This was also raised by other trusts in their discussions with the review team.

Home Oxygen

The Home Oxygen Service Assessment and Review (HOSAR) service has now been funded and is being rolled out across the Belfast HSC Trust. There is access to the full range of oxygen delivery services including concentrators, self-fill and ambulatory oxygen.

Oxygen assessments are being carried out and the team intends to provide six week oxygen reviews routinely after discharge. The teams have access to hand-held blood gas analysers. Overuse of oxygen in the home is a continuing issue. Community teams consider that support and a new way of working is required involving both community pharmacists and GPs to address this. Other areas that the Belfast HSC Trust community respiratory service wishes to focus on are the high cylinder users and patients' dependency on high flows of oxygen.

Medical Support

There is an appropriate level of non-medical prescribers in the respiratory team, though the trust plans to increase the proportion of non-medical prescribers. The trust reports that tele-health is working well for specially selected patients.

The review team found that overall there is good medical support provided for the community respiratory service, which could be further developed and improved through closer communication and integration with primary care. The ICP planning team has proposed a solution which would include groupings of general practices with a nominated lead for each cluster of practices.

The review team was presented with evidence of audits and research.

There was a very low level of patients' complaints.

2.4 Northern HSC Trust

Workforce

The Northern HSC Trust has 12.7 WTE staff in the community respiratory teams including physiotherapists, nurses and band three support staff; and includes 2 WTE HOSAR staff (funded non-recurrently for two years only). The service will expand with an additional 8.8 WTE staff, non-recurrently funded for one year. The number of staff available per 1,000 people with COPD is lower than most other trusts and the large geographical spread of this trust does need to be taken into consideration, in the provision of community home-based services.

Community Respiratory Service, Structures and Teams

The community respiratory service has three well integrated teams working across the trust. The trust described examples of good multidisciplinary team working and outlined well established links with both acute and community services. The review team also noted the links with the palliative care service. The community teams have identified a lack of occupational therapists within their structures. The review team sees the integration of occupational therapy as an important step towards improving the service.

It was reported that the current teams had insufficient staffing levels to integrate with primary care. The teams reported they would like to further develop links with GPs in respiratory conditions. It would be beneficial to have a named respiratory lead in each practice. An increased liaison with primary care should lead to more patients being aware of the service provided by community respiratory teams.

An acute assessment unit involving GPs has been in operation for the last two years and continues to develop. The availability of this unit allows patients in the community to be assessed rapidly, with access to diagnostics such as scans, x-rays and blood tests. This helps to prevent an attendance at an accident and emergency department, or an acute admission.

The respiratory team reported having very good access to medical consultants for advice. The team was keen to assure reviewers that all staff work as an integrated unit in the Northern HSC Trust.

There are a number of gaps in the ability of the existing team to provide the range of services which should be provided and are provided particularly for COPD in the other trusts. The ICP reported that they had to limit their service development proposal due to the constraints of the TYC process. They would have wanted to increase the number of staff further and also to include a specific ILD post; however, this would also need to be on a permanent basis.

At the time of the review the trust provided no out of hours service; however a plan, involving recruitment of staff, has been developed for the

commencement of this service supported by non-recurrent TYC funds. The service will provide an evening service up to 7 pm each weekday and a weekend and bank holiday service from 9 am to 3 pm during the period that is temporarily funded. Their remit would include provision of early discharge support and providing a rapid response service to GPs.

The Northern HSC Trust hopes that TYC funding will improve the links between and increase support from GPs. The funding will allow a permanent presence in each locality. The trust states that with more consultants in post, it would be able to respond faster to the increased need for the service. The Northern HSC Trust has a named consultant lead for ILD, supported by an acute respiratory nurse specialist with an interest in ILD, running a twice monthly clinic. The trust believes that a weekly clinic is necessary which will require increased consultant input.

The workload of the team consists mostly of referrals for people with COPD or bronchiectasis from acute care and some referrals from GPs. The team can discharge patients from the service, with the exception of patients with pulmonary fibrosis as they may deteriorate quickly. Discharged patients may self-refer back into the community respiratory service, when required. Nurses in the community respiratory service also provide nurse-led clinics, with consultant support, for COPD and asthma, in both the main acute hospitals and in the smaller community hospital sites.

All respiratory teams meet every four to five weeks to discuss service developments and resolve any outstanding issues. Staff reported no line management or professional lead problems. The reporting arrangements work well and are well integrated.

When possible, the community respiratory team tries to bring patients who are mobile to clinics. Other patients, where appropriate, are seen at home. Staff report that home visits are sometimes short, due to caseload commitments. On occasions there has been a need to contact patients to apologise for not visiting, as other patients have taken longer than expected. The trust teams feel that it is important to provide an adequate amount of time for each patient.

The trust's early supported discharge team only sees patients for the first two weeks post discharge and the community respiratory service aims to see any patients with respiratory diseases at a clinic within six weeks. A pilot was established in late 2014, in the northern sector of the trust, using the COPD discharge bundle and telephone review, before making home visits or bringing patients into clinics.

The community teams reported a wait of six months to a year for a chair lift assessment in the southern sector and nine weeks for an occupational therapist assessment in the Ballymena and Antrim area.

The trust described the excellent support received from the psychology team. Psychologists attend rehabilitation classes and are available to see patients in

their homes before they commence rehabilitation classes, if required, and also see patients requiring palliative care at home.

Northern HSC Trust reported that within the patient's home there are no delegated tasks. At pulmonary rehabilitation classes six minute walk tests are delegated as well as patient supervision within the pulmonary rehabilitation class. At oxygen clinics ambulatory assessments are delegated. Band three respiratory support workers carry out all of these delegated tasks with the support and under the supervision of the physiotherapy or nurse professional.

Obstructive Sleep Apnoea Hypopnea Syndrome (OSAHS) Services

The Northern HSC Trust has recently been funded to develop a local OSAHS service. The funding is limited for the provision of CPAP (Continuous Positive Airways Pressure) equipment. This trust provides only 70 urgent assessments for CPAP each year. The trust described long waiting lists for this service. Historically, OSAHS services for Northern HSC Trust residents were provided by the Belfast HSC Trust. There are very long waits of 18 months to access CPAP equipment from Belfast HSC Trust.

Pulmonary Rehabilitation

All three teams provide pulmonary rehabilitation classes running across nine locations throughout the trust area. The teams report, however, that it is not always possible to commence within one month of discharge. Due to the large demand, some locations run classes back-to-back to increase efficiency. One pulmonary rehabilitation class is followed by a shared education session, followed by a second pulmonary rehabilitation class, which appears to be a very efficient way of running classes. The education session can cater for twice the number of patients when compared with the pulmonary rehabilitation class. Staffing levels currently limit the ability to provide pulmonary rehabilitation in a timely fashion. The review team was told that the PHA is working with health promotion staff in local leisure centres to provide maintenance for patients with a respiratory disease. Most patients come from acute consultant referrals, but the team was also proud to have provided their first class to patients who were all referred from general practice.

In Magherafelt, cardiology patients share trust facilities with pulmonary rehabilitation classes. It was noted that suitable equipment was provided for outdoor exercise for cardiology patients. A suggestion was made by community teams that suitable equipment could also be provided for patients with a respiratory disease.

The dropout rate at classes had been considerable. The community respiratory service now undertakes telephone triage to ensure the appropriate selection of patients and to encourage patients to commence their rehabilitation. The classes are not only for those with COPD - in this trust people with a variety of respiratory conditions can attend. People awaiting lung transplant also attend maintenance classes. Patients can self-refer back into pulmonary rehabilitation classes after 12 months.

Communication

The team writes to the patient's GP following discharge and after their first assessment, with letters being transferred onto the ECR. Northern HSC Trust teams report being able to add information into the ECR via the Patient Administration System (PAS) uploads as well as having read-only access to patient records. The review team was informed that, in future, letters uploaded onto the ECR would be emailed directly to the GP. HSC trust staff reported that having to contact general practices by telephone was very time-consuming.

Cross Team Working

An example of integration in the trust was the development of Hospital Diversion Nurse Teams, consisting of general nurses with some respiratory training. They undertake intravenous medications and respiratory assessments, and will contact the community respiratory service if concerned about a patient. There were also good links with the acute response service.

The trust employs senior nurse practitioners within the district nursing service, long-term conditions (LTC) team, who also look after patients with respiratory disease. Informal linkages have been developed but the review team found no agreed protocols as to how patients were seen by each particular team. The respiratory team reported it could be difficult to transfer patients to the LTC team due to the volume of their caseloads. The trust team identified that this area needs an agreed discharge policy to indicate when to transfer patients between the trust's own community teams. The senior nurse practitioners were operating independently of the specialist community respiratory team. There was no shared education or training between community respiratory staff and the senior nurse practitioners. The review team considered that the role and function of the senior nurse practitioners in complex respiratory disease needs to be reviewed.

Bronchiectasis

Patients are encouraged to administer their own intravenous medications, although older people do not avail of this option. The physiotherapist visits all patients who are on intravenous antibiotics at home. The respiratory nurse supporting the bronchiectasis service is trained to insert long lines, with hospital diversion nurses trained in mid line insertion, but this places an additional workload on already overstretched teams. A pilot has been established involving a nurse and a physiotherapist holding a joint bronchiectasis clinic. The proposed funding does not include staffing for a fully integrated bronchiectasis services.

Palliative Care

The review team was told that a district nurse is still the best placed person to support palliative care patients and remains the key worker, even when the community respiratory team also looks after the patient. People with motor neurone disease (MND) who require NIV are commenced on this on an individual patient basis. Often these people have advanced disease and limited mobility and a local service is most convenient for them.

The Northern HSC Trust currently only commences non-invasive ventilation for patients with other neuromuscular disease who arrive acutely unwell in the hospital. The numbers are small but the cases are very time-consuming. Community respiratory nurses provide training for patients with non-invasive ventilation in nursing homes. For patients who are ventilated and those with a tracheostomy, the teams find the volume of training difficult as the turnover of carers is high. While the respiratory service is provided to these patients, it is completely unfunded.

The team reported some difficulties providing palliative care services for patients who are housebound. A referral to the hospice nurses network requires palliative care consultant input. Respiratory teams are not able to contact palliative care consultants directly and usually refer initially to a palliative care nurse. Cover for the last few days of care in a patient's home is restricted by funding. Respiratory consultants are always contactable by respiratory teams and will give advice, when asked to do so.

The hospice triage system causes the community respiratory service some concerns because of delays for some patients. A fax referral system is still in place, and although advice is always available, it usually takes a couple of days to a week before the hospice team visits the patient. The review team considered that a more responsive service should see a palliative patient the same day, especially for patients with ILD.

Home Oxygen

Trust staff reported that correct oxygen prescribing was working well in the community respiratory service. A good support network had been developed which includes two ward-based respiratory nurse prescribers, although winter pressures makes provision of this service in hospital challenging - as it is very laborious. The service is proactive and willing to stop inappropriate oxygen, when identified. The HOSAR service is funded non-recurrently only. Currently, two clinics are in operation and two new staff are being recruited. Efficiencies in provision of oxygen are already being made.

Training and Education

Trust staff outlined training undertaken by teams. An advanced communication course is run three times a year and everyone from consultant level to the newest team member completes this training. The team also reported completing end of life care and palliative care training.

Physiotherapists have access to an MSc course at the University of Ulster and the nursing staff access commissioned courses at the University of Ulster and Queens University, including specialist practice, COPD modules and prescribing course. The community respiratory service has completed many audits and a recent audit of rehabilitation conducted by physiotherapists was promoted at a trust internal audit day.

Telehealth

Some patients were described by staff as becoming somewhat obsessed by telehealth and had purchased their own pulse oximeters, where this was not

required. There was agreement that not every patient with a respiratory disease should have access to telehealth, as it increases anxiety in some patients. Some patients did not remain on telehealth for long and left after four weeks. In the trust, a physiotherapist is piloting a web-based programme offering remote pulmonary rehabilitation.

2.5 South Eastern HSC Trust

Workforce

The trust has 12 WTE staff in the community respiratory service and plans to increase capacity with an additional two WTE for the HOSAR service. This will then equate to 2.7 WTE staff per 1,000 people with COPD. There is no out of hours service and the bronchiectasis service requires enhancement.

Community Respiratory Service, Structures and Teams

There are three different teams covering the four localities of the trust. The review team considered this service has a motivated and skilled workforce expertly dealing with a wide range of complex diseases. There is a 0.4 WTE dietician integrated within the community respiratory service in one part of the trust only. This is a very effective addition to that team.

The review team was informed that the community respiratory service in the South Eastern HSC Trust is not fully integrated. The review team was advised about line management issues, and several different professional and line management structures across the three geographical areas. The senior management structures do not appear to be integrated for respiratory services and this is affecting operational issues on the ground. The review team considers that respiratory services need to have greater priority for the South Eastern HSC Trust.

The review team was told that the three teams have different ways of working across the trust. Some teams carried out home visits only, while others provided clinics and telephone advice. The staff described different referral procedures for different sectors.

There were no opportunities for respiratory teams to meet together at trust level. Physiotherapists hold regular meetings; however nursing staff did not get the opportunity to meet with other respiratory nurses from across the trust. The North Down and Ards team maintains links with respiratory wards in the Ulster Hospital, although the review team believes they were only partially integrated due to management structures.

Acute respiratory nurses used to be part of the community rota when there was previously only one team. However, they are no longer integrated with the community respiratory service, creating a gap between acute and community teams.

The respiratory teams were also unhappy about different bandings across acute and community staff and this had lowered morale in the community

respiratory team. Job re-evaluation has been delayed due to Human Resources issues.

The trust reported an increasing complexity of patients with a respiratory disease and an increasing demand for services. The team also raised the availability of services for those with bronchiectasis disease. There is only a specific service in North Down and Ards locality of the trust and this requires additional staffing.

Patients can self-refer back to the service; although they may be officially discharged, the team described a flexible system in which closed cases are considered dormant rather than discharged.

All patients are referred directly into the community respiratory service and at a multidisciplinary team meeting patients would be allocated to either a physiotherapist or to a nurse for domiciliary care. The specific nursing, physiotherapy and appropriately shared roles within the team lacked clear definition and the review team considered that this affected patient care and team effectiveness.

The review team were told of issues with a lack of accommodation, lack of storage space and unsuitable locations for patient assessments.

Some cross trust boundary working was described to the review team. Bronchiectasis clinics are provided in both in the Ulster Hospital and community settings. The clinics are a mix of nurse only, physiotherapy and nurse led, in addition to multidisciplinary clinics with consultant and staff grades.

The respiratory teams described very good access to consultants and staff grade doctors in acute hospitals. Community satellite clinics are also provided by these staff. Difficulties were experienced by community staff regarding access to medical management for people with NIV. Links with primary care were described by everyone as excellent. There are General Practitioners with a special interest in respiratory diseases. One GP has two sessions per month with the North Down and Ards team.

South Eastern HSC Trust reported that they do not employ band three staff within the community respiratory service. Therefore there are no delegated tasks.

Out of Hours

There is currently no out of hours service provided, i.e. at weekends, public holidays or outside the hours of 9 am to 5 pm weekdays. The team informs the community nursing rapid response service about any patients they are concerned about. The trust's rapid response team provides good support but does not always have capacity.

The out of hours GP service has access to the ECR, but tends to admit patients if they do not know their full history. A new funding bid for seven day

working has been submitted but had not been approved. This will also address areas, such as:

- provision of physiologists for spirometry education and service delivery
- increased end of life care for people with COPD
- care bundles for COPD
- additional resources in bronchiectasis to provide a trust wide service
- extending pulmonary rehabilitation
- integration with consultants and GPs
- seven day working

Pulmonary Rehabilitation

Pulmonary Rehabilitation classes run all year round, except in one location where a short break is taken in the summer due to lack of suitable accommodation. The attendance rate varies significantly across the trust; some areas are known for poor attendance whilst other classes catered for much larger numbers. The reasons given by the trust are either patients having difficulties with travelling to different communities or lack of access to public transport. A pulmonary rehabilitation assessment is conducted before attending classes. Previously, the wait for assessment was nine months but this has been reduced to four weeks. There are some maintenance classes following pulmonary rehabilitation and are provided in local community halls and leisure centre facilities. However, this has financial implications and currently there is no funding for room hire in the community, if required.

Communication

Letters from clinics are sent to GPs and consultants. Community Respiratory staff can read patient information on the ECR but cannot add their own information. The exception is letters from bronchiectasis clinics which can be saved to the ECR using a template agreed with the GPs, containing only the information they consider to be useful. The team reported it is still a work in progress for all information originating from community respiratory clinics to be uploaded directly onto the ECR. Electronic referrals are being considered in the future.

Cross Team Working

Community respiratory staff described themselves as “in-betweeners”, frequently working in an advocacy role between the patient, GPs and secondary care consultants, ensuring that the patient gets the right treatment at the right time in the right place. This helped with planning in relation to palliative care. Recently seven patients were supported to die at home, the place of their choosing. There were links with district nurses, especially in relation to end of life care for patients with palliative care needs.

The review team was informed about three virtual ward teams, who look after discharged patients. Fifty per cent of these patients have a respiratory illness, along with other complex co-morbidities. In caring for these patients, there is much cross-over between the community respiratory service and virtual ward teams. Community respiratory teams receive a weekly email from the virtual ward team to help to identify patients with a respiratory disease.

The review team noted that the criteria for who looked after people with more complex respiratory disease were not well defined. The review team considered that the trust should establish a firm set of discharge criteria to ensure that patients are being referred to the most appropriate community team for further management. Patients living in the community should have similar ease of access to the community respiratory teams as the virtual ward team (direct contact via mobile telephone).

Training

Community respiratory staff have completed many different types of training. The trust was able to describe having participated in Sage and Thyme⁹, advance care planning, planning for end of life training, joint training sessions with palliative care teams, allergy testing, spirometry and advanced communication training. After participating in joint palliative care training with district nurses, respiratory nurses were more confident and needed to refer fewer patients.

The respiratory team requires psychology input as they have none at present. Occupational therapy input comes from core services and the waiting time for assessment is two months, although they try and see patients at the end of life sooner. A microbiologist provides additional training for the teams.

The level of non-medical prescribing with the teams was described as good.

Telehealth

The community respiratory service has 140 patients using telehealth across the four localities and three teams. The staff reported being encouraged to use this service although they knew it was not appropriate for all patients.

The review team considers that patients waiting for lung transplants are receiving a good service with a rehabilitation class and maintenance classes to keep them well prior to surgery. Post-surgery these patients have telehealth support and the patients have given positive feedback.

Home Oxygen

Non-recurrent HOSAR funding has just been approved. Previously, it had been an adhoc service. Clinics have already been established and the service is expanding its capacity and undertaking reviews. The new service was described as proactive, whereas previously it had been solely reactive. The trust also described taking blood gases in the community.

The review team believes the work of the community respiratory service should receive more publicity, which would be good for staff morale. The

⁹ *Communication training for all grades of staff on how to listen and respond to patients/clients or carers who are distressed or concerned particularly about end of life issues.*

review team was informed of presentations made previously to the Chief Medical Officer, and the Permanent Secretary.

Research papers had been written about telehealth and bronchiectasis. One of the team members had also been shortlisted as a finalist for Nurse of the Year.

2.6 Southern HSC Trust

Workforce

The Southern HSC Trust will have 2.2 WTE staff per 1,000 people with COPD. This is a lower level of staffing than in other trust areas. It has to be noted that it does not include the staffing for the HOSAR service, a bid which at the time of the review had yet to be submitted by the ICP. There is no specialist integrated bronchiectasis service in the Southern HSC trust. The respiratory team is known as the COPD team.

Community Respiratory Service, Structures and Teams

The integrated team provides a service across a range of respiratory diseases. The different team members are based in a shared office and benefit from effective and open communication. The community COPD service has developed links with primary care. The team also receives support from acute respiratory consultants. Communication was described as a two-way process, where consultants would call the community COPD team for advice during outpatient clinics.

The community COPD team described having a good relationship with, and had the support of, GPs in their area. GPs found this to be a very responsive service. There were excellent relationships between consultants, community teams and GPs. Palliative care consultants were also described as supportive. The team works with Macmillan nurses, heart failure and district nursing, and found them all to be helpful and cooperative.

Counselling, dietetics and occupational therapy are not provided by the community respiratory service. Referrals requiring this specialist input are forwarded to core trust services.

Consultants are considering development of a rapid access clinic.

The trust team raised the new Community Information System (CIS) as an issue and noted that frequent changes and the time it takes to update information are barriers to providing patient care. It may prove to be an excellent system in the future but while the staff do not have remote access there will be duplication, as staff have to make written notes, which then have to be entered onto the system. In the future, it is hoped that the wealth of information regarding patients with a respiratory disease can be shared across primary, secondary and community care.

Some GPs had provided rapid access telephone numbers for the community respiratory team so that they would not have to wait longer than 15 minutes for the GP to respond about urgent patient management.

The Southern HSC Trust has an acute care team at home, a pilot funded to look after over 65 year old patients, providing a short intervention of 10 to 12 days, delivering care and bringing in other services, where appropriate. The respiratory team works collaboratively with this team for those patients with a respiratory disease.

A consultant geriatrician is the clinical lead for the Acute Care at Home Service and takes responsibility for intravenous antibiotics for patients over 65 years old.

The COPD team reported that it was a challenge for them to provide a similar service for patients under 65 years as the team would have to engage with respiratory consultants to provide intravenous antibiotics in the community. Phase one of the Acute Care at Home Service has included the Armagh / Dungannon and Craigavon / Banbridge localities as well as 47 private nursing homes, with approximately 1500 beds. A funding proposal has been submitted for phase two of the service. The trust COPD team described this service as being very successful.

All community COPD teams participate in early supported discharge which is fully integrated into their service. Primary care referrals are accepted directly by respiratory teams.

Southern HSC Trust reported that delegated tasks are part of home pulmonary rehabilitation. This is offered to housebound patients, post exacerbation. The patient is assessed by a nurse or physiotherapist and an individualised programme developed which aims to enhance recovery to the point where the patient may be well enough to come to a group pulmonary rehabilitation programme. Home rehabilitation programmes are delivered by the COPD rehabilitation assistant in the home setting. The programme is designed and outcomes are reviewed by the respiratory nurse specialist or physiotherapist. Maintenance rehabilitation is undertaken in a community based setting by the COPD rehabilitation assistant.

Out of Hours

There is no cover provided at weekends, but across the three localities a new service is planned. From 11 am to 4 pm one member of staff, either a nurse or physiotherapist, will be on duty in each locality on Saturdays, Sundays and bank holidays. The trust wishes to extend this to full working days.

Telehealth

Telehealth is provided for appropriate patients in the Southern HSC Trust. The team believes this monitoring service prevents admissions to hospital and recurrences of emergency department attendances. In rural areas, due to a lack of public transport, patients are likely to remain on telehealth for longer. Patients can contact the team for advice, care and results. Initially, the team

promotes telehealth as a short-term measure, but it can be difficult to persuade some patients that they no longer require this type of service.

Caseloads

There is one manager responsible for the physiotherapists and nursing team members. All referrals come directly to the team and any member of the team could be allocated to make initial contact with the patient. Either a nurse or physiotherapist will carry out an initial assessment. In the team's open offices communication is easy which facilitates sharing of information regarding the patients' conditions. Each team member is aware of the other members' strengths and weaknesses and the open offices assist shared learning.

Approximately 50 per cent of the COPD teams' time is spent with patients. Face to face contacts range between two to six patients per day. The COPD team undertake virtual patient consultations by telephone and via telehealth review on a daily basis. Some patients are seen at home, utilising joint visits by a nurse and a physiotherapist, if required. The team recognises that if patients, where possible, are seen in outpatient clinics, this provides greater capacity allowing for more patients to be seen. The COPD team also emphasised that outpatient appointments and care provided at these clinics are also appropriate.

The COPD team usually gets between one and two days' notice for discharges and keeps an active and non-active caseload. The team will discharge a patient if appropriate and patients can self-refer back into the service. The team reported that the caseload is both monitored and managed, with a good flow of patients both in and out. Referrals are monitored daily to ensure no patient is missed and administrators contact remote staff to flag urgent patients.

Access to the ECR has reduced the workload of the team. Twice daily downloads of data, ensure that teams have up to date information (although read access only) e.g. laboratory results, hospital letters, out of hours contacts, clinic letters, etc. Not all teams in Southern HSC Trust have access to the ECR. TYC was credited by staff as the driving force to enable access.

Palliative Care

There is 0.8 WTE consultant time in palliative care medicine allocated to community based activity. The palliative care team provide a clinical buddying programme which provides advice and support regarding palliative and end of life care when required by the COPD team. A number of staff within the COPD team have undertaken enhanced palliative care training.

There is an annual appraisal for all staff; operational issues are dealt with through the line management structure and professional matters are dealt with through other channels. There was a good understanding of professional relationships and everyone was able to recognise their scope of practice. The review team considered that the community team was very well integrated.

Home Oxygen

Some staff have completed training for oxygen assessment, while the remaining staff are currently undertaking this training. This will enable the team to measure blood gases in a patient's own home. The team has its own portable blood gas machine to be used for patients with a respiratory disease. When oxygen clinics are up and running they will be staffed by a nurse and a physiotherapist working in a joint role. The trust's proposal to establish a HOSAR service will be submitted to the commissioners. Venues for HOSAR have already been agreed. The trust's delay in submitting their bid has allowed them to learn from other trust's experiences.

The trust was not using self-filling oxygen equipment enough. More patients using self-fill equipment at home helps to reduce the cost of ordering more oxygen cylinders and therefore releases funding.

Pulmonary Rehabilitation

There are six community programmes and two acute programmes for pulmonary rehabilitation. Uptake of pre-programme assessments is high. The review team found that staff were willing to change practice in line with changing evidence. Home pulmonary rehabilitation is available when required. Maintenance pulmonary rehabilitation is delivered in all three localities, by the rehabilitation assistant, supervised by a specialist nurse or physiotherapist. Patients can self-refer into the full programme and are encouraged to do this if their disease state changes. Patients awaiting transplants participate in ongoing rehabilitation.

Gaps

The review team identified a gap in the service, as the respiratory team has to refer patients to other services for counselling, psychology and psychiatry, each of which have their own waiting lists. The psychology service only accepts consultant to consultant referrals. Agreed referral criteria, developed over eight years ago, are published on the trust intranet, and are available to everyone.

Staff indicated that they needed to increase their self confidence in non-medical prescribing. Time is made available to staff and support given to do this. The review team would like to see the community COPD teams' confidence increasing.

2.7 Western HSC Trust

Workforce

The trust has 19.0 WTE in the community teams. There is no planned increase in the staffing levels. The availability of staff per 1,000 people with COPD compares favourably with other trusts. This figure only takes into account physiotherapy input into pulmonary rehabilitation in the southern sector. The large geographical area of this trust also has to be taken into consideration when developing an effective community service.

Community Respiratory Service, Structures and Teams

Patients with a respiratory disease have become a target group for the trust in order to reduce hospital admissions, by managing patients better in the community. The current system needs the patient to have been admitted to hospital before they can be seen by the team.

There are currently three separate teams providing services:

- Early Supported Discharge
- Pulmonary Rehabilitation
- Case Management

In June 2015, the Western HSC Trust planned to re-organise the current early supported discharge and case management teams into three community respiratory teams. These three teams will cover the localities of Fermanagh, Tyrone and Londonderry. The team in Omagh will be established first, as the staff from early supported discharge and case management already occupy the same office in Omagh.

The review team met with nurses and case managers; unfortunately no physiotherapists, although invited, were available to meet with the review team. Trust staff reported that acute and community services are well integrated despite the current structure.

Physiotherapists are not part of the existing respiratory teams. The review team was informed that generic community physiotherapists or hospital physiotherapists, external to the team, provide support for patients. There is specific respiratory physiotherapy provided for pulmonary rehabilitation in the community in the southern sector (pulmonary rehabilitation in the northern sector has been excluded from the staffing analysis as it is provided from acute services).

The current team structure means that there are some gaps in provision of the full range of services provided by the different teams and in available skills across the teams. The new enhanced training and reorganisation of teams has been designed to close these gaps. The other factor noted by the review team was the lack of band seven specialists to provide clinical leadership within these teams.

Gaps will persist in the provision of an integrated bronchiectasis service across acute and community. Particular difficulties in the community respiratory specialist team relate to the separation of physiotherapy services. Issues relating to ILD and NIV are described in a separate section.

Response times for personal care are usually at least 48 hours. The trust's reablement project is improving trust response times. An early supported discharge team (ESD) sees the patient the next day. The ESD team is continuously supported by respiratory consultants. After a designated interval GP becomes the lead clinician. Unwell patients or patients requiring

telehealth, on the caseload of the respiratory service, can be seen the same or next day.

The respiratory team sits within a wider multidisciplinary team in the Western HSC Trust. Trust staff described links with palliative care, occupational therapy (non-respiratory), dietetics, social work and pharmacy. A pharmacist has been appointed to assist general practices in the northern sector review respiratory medicines and help with any issues which may arise for patients. The review team thought this was innovative and positive.

Waiting times for occupational therapy to provide triage and assessment are six months in the northern sector and nine months in the southern sector. If the service is required for a patient needing palliative care the patient is seen in a timely manner.

Secondary and primary care services work well together to ensure services are planned and integrated. The trust's respiratory consultants were complimented for their leadership skills. The GPs described the services as "the jewel in our crown."

The following factors were listed as preventing the teams delivering the best possible service:

- time and money
- many locations without any wifi connectivity
- the rural nature of the trust's catchment

The trust has two clinical intervention centres which are used by rapid response nurses e.g. for intravenous medications for patients that can travel to a more local facility rather than to a trust hospital. The trust considered that the new respiratory teams could also make use of these facilities. In Strabane, where there are limited HSC facilities, a respiratory nurse and case manager use a local leisure centre for pulmonary rehabilitation classes. Prior to that, along with an acute physiotherapist, they used a nearby church hall for pulmonary rehabilitation. The team emphasised the benefits of providing care in patients' homes, one of which would be to better assess compliance.

Western HSC Trust reported there is no delegation of tasks within the community respiratory services.

Medical Support

The team stated they had good links with and support from both GPs and consultants. A consultant or registrar was readily accessible for advice and reviews. The trust's virtual clinic had access to an advice line to contact the acute medical assessment unit in either hospital. A weekly multidisciplinary meeting was held in Ward 3 in Altnagelvin. The South West Acute Hospital (SWAH) does not have a respiratory ward and for patients discharged from SWAH contacting consultants was more difficult.

Some general practices had a yellow flag system as a means of highlighting patients with respiratory diseases and some GPs had provided the respiratory teams with telephone contacts, to make communication faster and easier. GPs now invite respiratory nurses along to ICP meetings; this was described by the nurses as being beneficial.

The review team was informed that some of the finer detail still needs to be resolved with district nursing teams, regarding who is best placed to deliver care for patients with respiratory disease. Palliative care services often support the respiratory team and have co-worked with respiratory staff to provide care for a number of patients.

Out of Hours

The northern sector operates a seven day a week early supported discharge only service, with reduced hours on Saturdays and Sundays (10 am to 2 pm), provided by a single nurse. The southern sector relies on the goodwill of respiratory nurses to see patients at weekends, and only if requested by a consultant. There is a plan to develop seven day working (10 am to 2 pm) across the whole trust. There was a suggestion that a 9 am to 5 pm service seven days a week would be ideal but as yet there are no costings for this service and it would also require new relationships to be developed with district nursing and out of hours GP services.

Caseloads

Initially, patients would have stayed with the case management service until the end of their life, but the service became overwhelmed. Currently, if patients meet certain criteria they are discharged back to their GP who has the option of re-referring them at a later date. Patients are not able to re-refer themselves.

With a low turnover of patients, caseloads have been capped at 52, as patients are living longer and are more complex. Approximately 50 per cent of patients are in the last year of their life. The team responds to acute deterioration of patients and early supported discharge patients, who can refer themselves to the respiratory team. The priority for these patients is prevention of admission.

There is a risk that patients may be readmitted during the night or at weekends due to the limitations of current information systems which do not contain current patient care plans.

There are mixed views from the GPs regarding the use of rescue medications and just in case medications (treatments for exacerbations and end of life e.g. patients keep a supply of steroids or antibiotics at home and can commence immediately they feel unwell). Following acute consultant advice, and as the patients involved are well known to them, nurses can prescribe. Acute consultants are the named mentors for nurse prescribers and are very supportive; GPs also support the provision of nurse prescribers.

Pulmonary Rehabilitation

Pulmonary rehabilitation is a nurse and physiotherapy led service. Within the northern sector it is provided by the acute services, and by the community services in the southern sector. It is planned that in the future this service will be delivered entirely by the new community respiratory teams. Waiting times for pulmonary rehabilitation have been dramatically reduced from an 18 month wait to six months for the northern sector and six weeks for the southern sector. All HSC professionals can refer to pulmonary rehabilitation. Classes held in the community have a better attendance rate due to easier parking, shorter walking distances from the car park to the class, etc. These classes are run in partnership with the British Lung Foundation and Breathe Easy. Maintenance classes are not available in the southern sector. In the northern sector only, there is a 12 week fitness class, provided free of charge. The Northern Ireland Chest Heart and Stroke Association runs an exercise programme on Thursdays in the southern sector.

Patient Records

Paper records used by the team are shared between team members in the offices. Everyone has read access to the ECR, but only acute and primary care staff can update patient records directly. Currently, the referral management system is being replaced by a new Clinical Communication Gateway (CCG) system. PARIS (a community information system) is being introduced for other services and will be made available to the respiratory teams in the future. The poor availability of mobile connections, internet and wifi hampers use of technology.

Training

The respiratory team undertakes a wide range of training, including palliative care / end of life care, has opportunities to work in Foyle Hospice to gain experience, and attends monthly Macmillan and GP training meetings. Supervision is provided for all community respiratory staff, which identified that end of life care training was required. In particular a two hour education programme for the team is provided by the GP Macmillan facilitator every month to enhance palliative care skills. This will ensure that patients with advanced respiratory disease receive palliative care as well as those who have lung cancer. A GP with a special interest in respiratory disease led the training and provided guest speakers. A training needs analysis has been carried out to ensure that all staff are trained to the required level. Staff members in the early supported discharge team are already highly skilled in respiratory disease.

Telehealth

Telehealth is suitable for some patients, but not for all. Patients who are proactive in their own self-care get more from the service. While telehealth can reduce anxiety in some patients, it is the reverse for other patients. Triaging of patients' phone calls is an important part of the service, as it reduces the number of calls forwarded to the respiratory team. Telehealth staff are able to deal with other issues which reduces unnecessary calls to the respiratory team i.e. equipment malfunction.

Home Oxygen

Patients are assessed by the hospital team and managed by acute respiratory specialists. Training has not yet been rolled out for this service. At the time of the review, two nurses had been appointed using non-recurring funding, one in the northern sector and one in the southern sector. Previously some patients have been provided with oxygen who do not need or are not using it; the trust is presently assessing these patients. There are a number of patients in the Western HSC Trust that are using self-filling oxygen. The home oxygen service is working very well and is cost effective.

Patients with bronchiectasis are cared for by the rapid response team. There is a designated bronchiectasis physiotherapist within the acute service working in the northern sector. No patients with a respiratory disease self-administer intravenous medications in this trust.

The review team considered that research and publications produced by the respiratory teams were commendable, and should receive more publicity.

The review team was also impressed to hear of a patient choir, 'Warbling Wheezers,' initially funded by the British Lung Foundation, is now an independent support group for patients. The choirmaster, pianist and admin support are all volunteers. The links with the voluntary sector in general are very good.

Section 3 Regional Gaps in Service

The review team identified that in Northern Ireland there were significant gaps in services for people with ILD and NIV. A combined regional and local approach is required for NIV and ILD. This section describes existing services.

3.1 Non-invasive Ventilation (NIV)

This refers to methods of providing ventilatory support to a patient without placing an artificial airway in the main windpipe (trachea). This is usually achieved by fitting a mask covering the nose or mouth and nose, or using nasal tubes or a mouthpiece, which is connected to a ventilator by tubing. The ventilator detects when the patient tries to take a breath in and delivers an extra flow of air to increase the volume of air inhaled. Community NIV is where this type of ventilation is provided to the patient in their own home.

Conditions that require a tertiary service

Certain conditions require specialist tertiary input. These include spinal cord injuries, kyphoscoliosis, transitional service provision (movement from paediatric services), neuromuscular conditions e.g. Duchenne Muscular Dystrophy, etc.

Motor Neurone Disease is a disease suitable for shared care as it is rapidly progressive and people may not be able to travel. This may be the case for other complex diseases as the condition progresses.

People with other conditions such as OSAHS, COPD and obesity hypoventilation services are usually cared for locally. However some of these conditions may require tertiary back-up for complex aspects of care.

Local Drivers

- Increasing indications for community NIV and markedly increasing numbers, with no planned service model, provision, or funding, has created a number of urgent and ongoing operational issues for the service.
- NICE guidance¹⁰ CG105, for NIV in MND has been approved for use in Northern Ireland.
- Transition to adult services particularly for Duchenne Muscular Dystrophy.
- New devices have become available with an increasing evidence base for the efficacy of these treatments e.g. cough assist devices, which have no funding mechanism and therefore are difficult to procure to improve quality of life and reduce admissions.

¹⁰ <https://www.nice.org.uk/guidance/cg163> June 2013

Availability of services in each trust

Belfast and Western HSC Trust areas both have consultant and nurse specialist expertise to provide a specialist tertiary service. Both services provide regional and local service provision. They provide inpatient facilities, clinics to review patients and outreach, as required. There is no specialist physiotherapy service available. The Belfast HSC Trust specialist NIV nurse outreaches to Northern, South Eastern and some Southern HSC Trust residents for complex regional issues. Both trusts have difficulties in providing regional and local services due to increased numbers. There is no transition pathway from paediatric services.

The South Eastern HSC Trust starts people on home NIV on occasions following an acute episode that requires hospital admission. This may be for respiratory or neuromuscular conditions. There is no identified consultant lead for NIV within the South Eastern HSC Trust and no structured provision for community follow-up.

The Northern HSC Trust is increasingly providing a local service for people with respiratory conditions, since the development of overnight oximetry services has been provided. People with MND who require NIV are commenced on this on an individual patient basis. Often these people have advanced disease and limited mobility and a local service is most convenient for them. The Northern HSC Trust currently only commences non-invasive ventilation for patients with other neuromuscular diseases who arrive acutely unwell in the hospital.

The Southern HSC Trust has several consultants who manage people with non-respiratory conditions. A respiratory physiotherapist supports anyone whose treatment begins locally. There is no local specialist respiratory nurse support. People with respiratory conditions are commenced on NIV locally. Increasingly people with MND are started and maintained locally, but this is causing a number of problems because of the lack of a local multidisciplinary neuromuscular community support team.

There is a marked increase in the number of people with conditions which should be looked after locally. There are capacity issues, particularly in respiratory nursing and physiotherapy services in the community, in all trust areas for people with NIV.

Many people on NIV with neuromuscular conditions have highly complex needs. One issue for all trusts is the lack of input from a specialist neuromuscular service (medical, nursing and physiotherapy) in the community to provide multidisciplinary support for specific disease management aspects, including disease progression and palliative care support for many conditions. Local respiratory services could provide NIV support for those who are unable to travel, but cannot have expertise to cover other aspects of these conditions. MND does have one adviser available regionally and a second person is being appointed to a research role.

In July 2014, in an internal PHA paper on complex home ventilation, the drivers for change and proposed model of service were developed. The paper details nine regional recommendations to support a tertiary service model and four recommendations for a local service model. To establish the equipment provision and funding, there are a further four recommendations. These recommendations are included in Appendix A. The review team fully supports these recommendations.

3.2 Interstitial Lung Disease (ILD)

ILDs are a collection of diverse conditions causing inflammation and/or scarring within the lungs. ILD affects the tissue and space around the air sacs of the lungs. Some ILDs have a known aetiology (e.g. asbestosis). Three ILDs contribute the largest impact on the population and the health service; idiopathic pulmonary fibrosis (IPF); sarcoidosis; extrinsic allergic alveolitis (EAA) now known as Hypersensitivity Pneumonitis (HP).

For those patients diagnosed with IPF, 50 per cent will die within three years from time of diagnosis. If classified as a malignancy, IPF would rank as the eighth most prevalent cancer worldwide and has a similar burden to ovarian and renal cancers.

NICE guidance¹¹, Idiopathic pulmonary fibrosis: The diagnosis and management of suspected idiopathic pulmonary fibrosis, has recommended provision of regional specialist ILD centres. Recommendations also have been made by NICE for development of local trust ILD multidisciplinary teams. Services include diagnosis, treatment, pulmonary rehabilitation, oxygen and palliative care.

Currently there is no regional specialist ILD service and there are no ILD nurse specialists in Northern Ireland. There are basic local trust services for patients with ILD. No trust has multidisciplinary team meetings, as recommended by NICE for ILD, or prescribing of high cost therapies. Northern and Western HSC Trusts have reorganised outpatient clinics so that people with suspected ILD attend a local dedicated respiratory physician. In the Northern HSC Trust a respiratory nurse attends their dedicated clinic. This nurse has recently completed an MSc at Liverpool which includes ILD. In other trusts people with ILD are attending general respiratory clinics, triaged to any of the consultant team.

Pirfenidone, the only available treatment for IPF, is being commissioned by the HSC Board as per the NICE technology appraisal¹². However, due to the lack of dedicated services early diagnosis is limited and therefore access to pirfenidone is also limited.

¹¹ <https://www.nice.org.uk/guidance/cg163> June 2013

¹² <http://www.nice.org.uk/guidance/ta282> April 2013

3.3 Commissioning and Service Development

Community Respiratory Services are already recognised as providing expert patient support services, very much in the model promoted by TYC. The ICPs commissioning specification for respiratory services was quoted as being a helpful document to support local planning and design of service.

The TYC proposals were generally agreed to have supported the further development of Community Respiratory Services within Northern Ireland. The development of ICPs was also seen as a positive step forward into integrated service planning and development, involving trusts, GPs and other primary care professionals, as well as the voluntary sector. Several ICPs reported that service development work was particularly easy for respiratory services, due to collaborative working relationships among all interested parties. The combination of local professional leadership, good working relations between ICPs and LCGs and available planned funding streams has led to successful proposals for integrated service development, some of which are already agreed and being progressed.

One of the difficulties reported by a number of those interviewed was the actual TYC process being used. Short-term funding, which is generally available on the basis of saving bed days, does not allow development of an integrated approach across primary prevention, primary care services, community and home-based services, secondary care services and palliative care. Such an integrated approach was considered to be essential to avoid disease development and progression, to avoid use of health and social care services in the long-term. Many people reported that this process did not allow quality of life issues to be properly addressed. This had led to ICPs in some trust areas developing very limited funding proposals, based on potential immediate bed days saved, rather than actual service needs.

Non-recurrent funding has affected the ability to recruit into posts and deliver services. The HOSAR service in particular had been developed on the basis that savings will cover the costs of providing the staff for the service. Without staff, savings will not be achieved. Some LCGs had other sources of funding to support a recurrent service.

Other development difficulties in some areas were reported due to complex commissioning processes. It was felt that the decision-making processes at the HSC Board and PHA were very slow. There appeared to be a lack of understanding about who makes decisions and in what detail at which level; there was lack of integration between different parts of systems, for example, financial planning and commissioning. It was reported that when savings were made in respiratory service provision they were not available for reinvestment in respiratory services.

The purpose of the ICP commissioning specification was to ensure that similar types of services are available regionally, allowing local variation as to how they are actually delivered. It was reported that some of the delays were due

to lack of understanding at the HSC Board and PHA level of the reasons and need for local variation.

However, it was stated that certain aspects should be delivered regionally, for example, development of regional criteria and systems for pharmacy and primary care education, to avoid duplication and ensure consistency.

One other commissioning issue reported was the difficulty in service development and funding across several trust areas or where service development proposals cross regional and local commissioning areas. Systems are not available to support this.

Section 4 Overall Conclusions

This review considered the work of specialist community respiratory teams. The review team was impressed with the quality and availability of community respiratory services across Northern Ireland. Some improvements are needed which will further enhance the range of services available and ensure equitable service provision. A number of recommendations have been made to this effect.

Community respiratory services are designed to provide services close to people's homes, or in the home. These services provide care and treatment to people with a range of conditions such as COPD, bronchiectasis, idiopathic pulmonary fibrosis, and provision of NIV services to those with respiratory and some neurological conditions to varying degrees across the five trusts.

Community respiratory teams should offer access to a range of prevention, social and emotional support services; enhanced supportive self-management; admission avoidance; exacerbation management; early supported discharge; pulmonary rehabilitation; oxygen services and palliative care.

They should support primary care staff and integrate closely with all primary, secondary and community care staff to ensure a co-ordinated and comprehensive response to people with these conditions.

Many of these services are provided in the home as part of the ongoing treatment. Where someone is able to attend a community outpatient clinic, this is appropriate to allow cost-effective provision of services, especially in rural areas involving long travelling times.

Service development proposals are currently being planned for extended working into the evenings and, provision of Saturday and Sunday availability.

The review team had to consider the wider context of provision of community services as these are only safe, effective and compassionate if provided as part of a fully integrated service.

ICPs are considering respiratory services as part of a TYC model and the work of the ICPs and commissioning processes were highlighted as important drivers impacting on current and future effectiveness of specialist community respiratory services. These aspects were examined within the review.

The community-based system working closely with primary care and reaching into secondary care was considered to be an excellent model and much more effective than in most other parts of the UK, where specialist respiratory services tend to be provided on an outreach basis from hospitals. The Northern Ireland model leads to a much more patient-centred service, providing effective care across the whole disease spectrum from new diagnosis to end of life care.

Generally, teams across the five HSC trusts are well integrated and have insight into how their service is operating. Staff are responsive, knowledgeable and have identified gaps and proposals for improvements in their services. They generally have produced solutions to address these.

GPs are supportive and appreciative of the work of the community respiratory teams in providing effective responses to enhance patient care.

The main delegation of tasks is the delivery of home-based rehabilitation programmes where the patient cannot attend group classes. This is supported and supervised by specialist staff.

4.1 Service User Views

Service users spoke highly about the staff and the quality of the community respiratory services they had received. They were well informed about how and when they could make contact with the community respiratory services. Their main issue was about lack of signposting and information about different types of services, for example, oxygen for travelling and availability of maintenance classes.

Key Recommendation 1

All HSC trusts, in partnership with primary care and the voluntary sector, need to provide better signposting of services for users and carers.

4.2 Belfast HSC Trust

Belfast HSC Trust has received additional recurrent funding to develop a more responsive service. When all staff are in post there will be 2.9 WTE per 1,000 people with COPD, covering an urban geographical area. This team has integrated occupational therapy and dietetic support, which works well. In future, it will also have integrated psychology services.

The review team found this service to be an exemplar of a community respiratory service. An excellent service was described by trust staff during a meeting with the review team.

It was noted that the Belfast HSC Trust had had ten years of continuous development, with a fairly consistent team. This has resulted in complete integration as one team. This team had dedicated time provided by occupational therapy, dietetics, as well as sessional input from GPs. There is evidence of good communication with GPs. Multidisciplinary working has been built into the service to provide an holistic approach.

Future developments will significantly increase the integration with primary care. There is strong medical support for the community respiratory service provided by respiratory physicians. The review team found good links

between the community and acute services, as well as across a range of community services.

Supporting Recommendation 1

The Belfast HSC Trust should continue to develop the respiratory teams' connections with general practices.

The funding proposal which was initially stimulated by TYC meets the commissioning specification across the spectrum. This has secured recurrent funding from different sources allowing the service to develop in a timely manner. The proposal is a comprehensive bid designed to cover gaps in the service, including case finding, primary care management, seven day services and home oxygen service assessment and HOSAR services.

The review team found the levels of line management to be appropriate across the service. Managers were effective and demonstrated good leadership.

4.3 Northern HSC Trust

Historically, specialist community respiratory team staffing levels have been at a low level compared with other trusts. This has affected the ability of the teams to provide the range of services which should be available, particularly for people with COPD and are already generally provided in other trust areas. Due to low staffing levels it has not been possible to develop links with GPs and practice nurses.

Staffing levels are planned to increase with recent TYC funding. This should enable some service gaps to be met, if additional staff can be appointed and staffing levels maintained. Community bronchiectasis services will still not be covered sufficiently. Funding is, however, only provided for one year non-recurrently.

The proposed number of staff per 1,000 people with COPD is low compared with the Belfast HSC Trust, and the large geographical area needs to be taken into account in the provision of community and home-based services.

This team does not have integrated occupational therapy and dietetics, which has led to difficulties in accessing core occupational therapy in particular. Psychology is not integrated, but access was not reported as an issue.

Key Recommendation 2

The HSC Board should examine staffing levels across the Northern HSC Trust area in the respiratory service, which should be sustainably funded, to see if there is appropriate provision of the full range of services across its large geographical area.

The trust described a good level of integration both within the team and also between the acute and community sectors such as the hospital diversion nurse teams. The review team considered that the proposed increased staffing levels would support better linkages with primary care. There was very good support provided by respiratory consultants.

The trust employs senior nurse practitioners within the district nursing service who also look after patients with respiratory disease. Informal linkages have been developed but the review team found no agreed protocols to decide on which patients were seen by each particular team. Senior nurse practitioners were operating independently of the specialist community respiratory team.

There was no shared education or training between community respiratory staff and the senior nurse practitioners. The review team considered that the role and function of senior nurse practitioners in complex respiratory disease needs to be reviewed.

Supporting Recommendation 2

In the Northern HSC Trust the role and function of the senior nurse practitioners in complex respiratory disease, needs to be reviewed with agreed protocols established, to ensure that patients are being looked after by the most appropriate skilled and trained practitioners.

Issues have arisen with the timely availability of the specialist palliative care community nursing services to visit patients in the home. The review team considered that a more responsive service is required.

Supporting Recommendation 3

The Northern HSC Trust should examine the effectiveness of the arrangements to ensure rapid access to specialist community palliative care nursing services in the patients' home.

4.4 South Eastern HSC Trust

When HOSAR staff are in post there will be 2.9 WTE staff per 1,000 people with COPD. This compares favourably with other trusts, but the larger geographical area has to be taken into account for the provision of services. This service has integrated dietetics in one team only. There are long waiting times from core occupational therapy services. There is no out of hours service and bronchiectasis services require enhancement.

The review team engaged with three teams with a high level of enthusiasm, skills and commitment to patients. However, the review team did not consider community respiratory teams to be integrated across the trust. Senior management structures do not appear to promote integration of respiratory services.

The review team considered the operational management of the team to be fragmented. This led to difficulties in operational integration across areas and between acute and community services.

Physiotherapists have a forum and one line management structure across the three teams but nurses have no such structure. The specific nursing, physiotherapy and appropriately shared roles within the team lacked clear definition and the review team considered that this affected patient care and team effectiveness.

Supporting Recommendation 4

Management and professional lines between different professional staff need to be reviewed to allow integration across the three community teams and across acute and community services, in the South Eastern HSC Trust.

Supporting Recommendation 5

Specific nursing, physiotherapy and appropriately shared roles within the team in the South Eastern HSC Trust need clearer definition.

There was duplication between virtual ward and the specialist teams, with a lack of agreed criteria setting out which patients are suitable for the virtual ward and which should be with specialist teams for more complex respiratory diseases.

Supporting Recommendation 6

In the South Eastern HSC Trust criteria should be developed for people with complex respiratory disease to ensure referrals to the most appropriate community team.

HOSAR funding has been received and the service has commenced.

Good linkages and support are available from senior medical staff. One area which the review team was concerned about was the lack of a nominated medical lead for NIV in the community.

Supporting Recommendation 7

The South Eastern HSC Trust should nominate a medical lead for NIV to support the community respiratory team.

There are issues with a lack of accommodation, storage space and suitable locations for patient assessments.

Supporting Recommendation 8

The South Eastern HSC Trust should review the accommodation requirements for the community respiratory team.

4.5 Southern HSC Trust

The Southern HSC Trust has 2.2 WTE staff per 1,000 people with COPD. This is a lower level of staffing than any other trust area. It has to be noted that it does not include the staffing for the HOSAR service, a bid which at the time of the review, had yet to be submitted by the ICP.

The specialist COPD team does not have integrated occupational therapy or dietetics, however the team do make referrals to core OT and dietetics if required. There is no integrated psychology input and this has been reported as providing difficulties in access.

The new proposed funding for out of hours will cover only five hours on Saturdays and Sundays, with no extended day-time working hours.

A fully integrated bronchiectasis service is not available.

Supporting Recommendation 9

The Southern ICP bid should be submitted as soon as possible for the HOSAR service in the Southern HSC Trust.

The review team considered that the Southern HSC Trust has one very well integrated community COPD team which is delivered over three locality areas. Staff morale was exceptionally high.

Joint working between the acute care at home team and the community respiratory team was a good example of effective communication and integration across the teams. There were excellent links with other teams such as palliative care, heart failure and district nursing.

Bi-monthly multidisciplinary team meetings are held. Support provided by and links with GPs and consultants were reported as excellent.

4.6 Western HSC Trust

At the time of the review the trust did not have a specialist community respiratory team. Due to historical structures, there were three separate teams, early supported discharge, pulmonary rehabilitation and case management. The Western HSC Trust had recognised that this structure did not provide the full range of services required for people with respiratory disease.

It is difficult to make definitive conclusions about the team size as account could not be taken of the total numbers of physiotherapy staff available. The review team noted that caseloads within case management were capped and that patients are not able to self-refer back into the service, once discharged.

The trust informed the review team that from 1 June 2015 a new structure would be put in place and, there will be a phased approach to implementation for community respiratory teams. There were recognised skills deficits in certain teams and there is no clinical leadership at band seven in the existing teams.

A training needs analysis has been carried out and training is being implemented to ensure provision of a comprehensive service across the trust area.

Community bronchiectasis services will still be limited.

Supporting Recommendation 10

The Western HSC Trust should ensure the plan to restructure the three community teams into one specialist community respiratory team is implemented without delay.

Supporting Recommendation 11

Clinical leadership at an appropriate level should be developed for the specialist community respiratory team in the Western HSC Trust.

In this trust, physiotherapy services are provided by core services and are managed completely separately. Physiotherapists should be an integrated part of a community respiratory specialist team and not provided from core services. Occupational therapy and dietetics are not integrated into the team and particularly long waiting times are described for core occupational therapy services. Psychology services are integrated into the team.

Supporting Recommendation 12

Specialist respiratory physiotherapy provision should be integrated into the specialist community respiratory teams in the Western HSC Trust.

Working practice across acute and community respiratory services and across other community services was well integrated. Excellent linkages and support from GPs were evident. There was good support from respiratory physicians in the trust area.

4.7 Generic Conclusions for Five HSC Trusts

Record Keeping and Sharing

Generally, apart from a few limited examples, community respiratory teams have difficulties in accessing patient information systems remotely. The limited access to read and write functionality within the ECR system across the five trusts affects the ability of a service to share relevant and up to date treatment plans across primary, community and secondary care.

Key Recommendation 3

The HSC trusts should seek full read and write access to the ECR system to improve the integrated working in community respiratory services across Northern Ireland.

Home Oxygen Services and Review (HOSAR)

Funding for HOSAR services has been agreed across four HSC trusts non-recurrently only. The Southern ICP is the only ICP that has not yet submitted a bid.

Staff are being appointed and, where staff are in post, significant improvements in services for patients, and cost savings, have been achieved. These savings have been estimated to cover the costs of providing the staff to run the HOSAR services recurrently.

Key Recommendation 4

The HSC Board should ensure that the HOSAR service is sustained and recurrently funded across NI.

Palliative Care

Community respiratory teams across Northern Ireland provide care for patients across the spectrum of disease, including end of life care. Non-cancer palliative care has been developing in recent years and the community respiratory specialist teams have been to the forefront in ensuring that they continue to look after people with respiratory disease until death. Training on end of life care issues has been provided across all trust areas, to ensure that staff can provide excellent care.

Many more people with respiratory disease are now supported to make choices about the care they wish to receive and where. Community respiratory specialist teams are well supported by other community services, GPs and specialist palliative care services.

Key Recommendation 5

Specialist community respiratory teams in all HSC trusts should continue to ensure that all patients with end of life care needs are identified and patient choices are supported.

Out of Hours

Out of hours services allow early supported discharge, prevent admissions and support those with end of life care needs. Some out of hours services are available in the northern sector of the Western HSC Trust; whilst three other trusts are progressing their developments. The new proposed funding for out of hours in the Southern HSC Trust will cover five hours on Saturdays and Sundays with no extended day time working hours. The South Eastern HSC Trust has not yet had agreement for funding to development its service. In the future, there will still be local variation in the hours the service is provided when these developments commence.

Key Recommendation 6

The HSC Board should continue to work towards equitable access for all service users in all HSC trusts specialist community respiratory services, to incorporate extended evening working and at weekends.

Pulmonary Rehabilitation

Pulmonary Rehabilitation services have increased markedly across Northern Ireland. There are some areas (Western and Northern) that still have long

waiting times. There was a high level of patient satisfaction with maintenance classes following pulmonary rehabilitation. These classes sustain physical fitness and emotional and social well-being, but are not yet available in the southern sector of the Western HSC Trust.

The review team was impressed with an additional telephone assessment prior to the routine clinical assessments conducted by the Western HSC Trust, prior to pulmonary rehabilitation. This proved to be successful in ensuring that selected patients actually attended pulmonary rehabilitation and completed their course of treatment.

Supporting Recommendation 13

The HSC Board should assure itself of equitable access to pulmonary rehabilitation and maintenance classes in all HSC trusts.

Bronchiectasis Services

Bronchiectasis services have variable levels of provision across the HSC trusts in Northern Ireland in the community, across trust localities and in acute services. Bronchiectasis services should be available and fully integrated across acute and community sectors. Specialist nursing and physiotherapy should be available to provide access (including self-referral) for prompt and appropriate management of people with more complex disease. Rapid access should be available to district nursing services for people who are not able to self-administer IVs.

Key Recommendation 7

The HSC Board should work towards the provision of a fully integrated bronchiectasis service in the Northern, South Eastern, Southern and Western HSC trusts.

The five trusts described different levels of integration of occupational therapy, psychology and dietetics within the community teams. Long waiting times for core services for occupational therapy were described in three out of the four trusts where this was not integrated into the teams. Two trusts in the future will have integrated psychology provision. Two other trusts described having marked difficulties in accessing psychology services. Where dietetics was integrated, it was found to be effective.

Key Recommendation 8

Occupational therapy, dietetics and psychology input needs to be an integrated part of the community respiratory team in each HSC trust area.

Training and Education

The review team was informed of a wide range of completed formal training and of the large number of opportunities for multidisciplinary learning and education.

Interstitial Lung Disease (ILD)

ILDs are a collection of diverse conditions causing inflammation and/or scarring within the lungs. It affects the tissue and space around the air sacs of the lungs. Idiopathic pulmonary fibrosis (IPF) is one of the three commonest types of ILD. Of those diagnosed with IPF, 50 per cent will die within three years from time of diagnosis.

NICE guidance¹³ has recommended development of regional specialist ILD centres. Recommendations also have been made by NICE for local trust ILD multidisciplinary teams.

Currently there is no regional specialist ILD service. There are basic local trust services for ILD patients. No trust has multidisciplinary team meetings as recommended by NICE for ILD, or prescribing of high cost therapies. There are no ILD nurse specialists in Northern Ireland. Only Northern and Western HSC Trusts have reorganised outpatient clinics so that people with suspected ILD attend a local dedicated respiratory physician.

Pirfenidone, the only available treatment, for IPF is being commissioned by the HSC Board as per the NICE technology appraisal¹⁴. However, due to the lack of dedicated services early diagnosis is limited and therefore access to pirfenidone.

Key Recommendation 9

The HSC Board should ensure the regional and local multidisciplinary services for people with ILD are established in line with NICE guidance.¹⁵

Key Recommendation 10

The HSC Board should assure itself that ILD is managed appropriately, in all HSC trusts, ensuring that suitably trained respiratory nurse specialists are available in each trust area to support people from diagnosis to end of life.

Non-invasive Ventilation (NIV)

The requirements for non-invasive ventilation in the community are increasing due to increasing indications and the development of new devices. Community services are required for those with specific respiratory disease and neuromuscular conditions. The role of respiratory teams is to manage the respiratory aspects of NIV. Particular difficulties have been experienced by respiratory teams due to lack of training and lack of available community neuromuscular support teams. Appropriate management of more complex neuromuscular conditions requires multidisciplinary input from a range of specialists across respiratory and neuromuscular disease.

¹³ <https://www.nice.org.uk/guidance/cg163> June 2013

¹⁴ <http://www.nice.org.uk/guidance/ta282> April 2013

¹⁵ <https://www.nice.org.uk/guidance/cg163> June 2013

A fully integrated service would require regional services for the most complex conditions; local expertise for those with less complex disease; and agreed shared care management of disease between regional and local services e.g. for those with complex conditions who are too ill to travel.

Regional services require to be enhanced for the management of complex disease and provision of support for local trust areas. All trust areas report difficulties in being able to provide a local service.

Key Recommendation 11

The HSC Board should commission recommendations from the internal PHA report Complex Home Ventilation in Northern Ireland (July 2014) to enhance the regional and local support services and equipment available for people requiring NIV in all HSC trusts. (See Appendix A)

Supporting Recommendation 14

The HSC Board should undertake a gap analysis of the provision of community neuromuscular services across all HSC trusts.

OSAHS

OSAHS services were traditionally delivered by the Belfast HSC Trust for Belfast, South Eastern and Northern HSC trusts residents. Funding has been made available to Northern and South Eastern Trusts to develop local aspects of this service. Certain aspects of service provision still remain with the Belfast HSC Trust. There are unacceptable waiting times for limited sleep study investigations and CPAP provision. There are major public and patient safety concerns due to length of waiting times.

Key Recommendation 12

The HSC Board should urgently ensure commissioning arrangements address the availability of appropriate and timely local OSAHS services in each trust area.

4.8 Commissioning

The concept of TYC was welcomed as an opportunity to develop further fully integrated respiratory services, particularly across primary and community care. ICPs were seen as a positive step towards integrated service planning and development. The ICP commissioning specification¹⁶ for respiratory services was quoted as being a very helpful document to support local planning and design of service.

¹⁶ HSC Board Commissioner Specification - Respiratory Services May 2013

At the start of the ICP process, most community respiratory teams required increased staff to deliver the range of required services, including HOSAR services, out of hours services and bronchiectasis services. The process adopted for TYC implementation, based on the immediate reduced bed days to fund service development, was widely criticised. It did not allow the full spectrum of services to be enhanced particularly for prevention, early detection and stable disease management which would reduce demand on services in future years. Much funding was short-term and non-recurrent which makes recruitment difficult.

A recurrent theme was that commissioning processes were complex, slow and not integrated across the different parts of the system. There was no development process for services which had both local and regional aspects.

It was stated that certain aspects should be delivered regionally, for example, development of regional criteria and systems for pharmacy and primary care education, to avoid duplication and ensure consistency.

Key Recommendation 13

The HSC Board should ensure that services are developed for respiratory diseases, which are fully integrated across primary, community and acute care; from prevention to palliative care.

Supporting Recommendation 15

The HSC Board should simplify the commissioning processes to allow appropriate levels of decision-making, in much shorter timescales.

Supporting Recommendation 16

The HSC Board should ensure commissioning systems support development processes which have regional and local aspects in respect of community respiratory services in Northern Ireland.

Supporting Recommendation 17

The HSC Board should develop regional criteria and systems in order to reduce duplication and ensure consistency in community respiratory services across Northern Ireland.

Section 5 Summary of Recommendations

5.1 Key Recommendations

Key Recommendations for HSC Board

2	The HSC Board should examine staffing levels across the Northern HSC Trust area in the respiratory service, which should be sustainably funded, to see if there is appropriate provision of the full range of services across its large geographical area.
4	The HSC Board should ensure that the HOSAR service is sustained and recurrently funded across Northern Ireland.
6	The HSC Board should continue to work towards equitable access for all service users in all HSC trusts specialist community respiratory services, to incorporate extended evening working and at weekends.
7	The HSC Board should work towards the provision of a fully integrated bronchiectasis service in the Northern, South Eastern, Southern and Western HSC trusts.
9	The HSC Board should ensure the regional and local multidisciplinary services for people with ILD are established in line with NICE guidance ¹⁷ .
10	The HSC Board should assure itself that ILD is managed appropriately, in all HSC trusts, ensuring that suitably trained respiratory nurse specialists are available in each trust area to support people from diagnosis to end of life.
11	The HSC Board should commission recommendations from the internal PHA report Complex Home Ventilation in Northern Ireland (July 2014) to enhance the regional and local support services and equipment available for people requiring NIV in all HSC trusts. (See Appendix A)
12	The HSC Board should urgently ensure commissioning arrangements address the availability of appropriate and timely local OSAHS services in each trust area.
13	The HSC Board should ensure that services are developed for respiratory diseases, which are fully integrated across primary, community and acute care; from prevention to palliative care.

¹⁷ <https://www.nice.org.uk/guidance/cg163> June 2013

Key Recommendations all HSC Trusts

1	All HSC trusts, in partnership with primary care and the voluntary sector, need to provide better signposting of services for users and carers.
3	The HSC trusts should seek full read and write access to the ECR system to improve the integrated working in community respiratory services across Northern Ireland.
5	Specialist community respiratory teams in all HSC trusts should continue to ensure that all patients with end of life care needs are identified and patient choices are supported.
8	Occupational therapy, dietetics and psychology input needs to be an integrated part of the community respiratory team in each HSC trust area.

5.2 Supporting Recommendations

HSC Board

13	The HSC Board should assure itself of equitable access to pulmonary rehabilitation and maintenance classes in all HSC trusts.
14	The HSC Board should undertake a gap analysis of the provision of community neuromuscular services across all HSC trusts.
15	The HSC Board should simplify the commissioning processes to allow appropriate levels of decision-making, in much shorter timescales.
16	The HSC Board should ensure commissioning systems support development processes which have regional and local aspects in respect of community respiratory services in Northern Ireland.
17	The HSC Board should develop regional criteria and systems in order to reduce duplication and ensure consistency in community respiratory services across Northern Ireland.

Belfast HSC Trust

1	The Belfast HSC Trust should continue to develop the respiratory teams' connections with general practices.
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Northern HSC Trust

2	In the Northern HSC Trust the role and function of the senior nurse practitioners in complex respiratory disease needs to be reviewed with agreed protocols established to ensure that patients are being looked after by the most appropriate skilled and trained practitioners.
3	The Northern HSC Trust should examine the effectiveness of the arrangements to ensure rapid access to specialist community palliative care nursing services in the patients' home.

South Eastern HSC Trust

4	Management and professional lines between different professional staff need to be reviewed to allow integration across the three community teams and across acute and community services, in the South Eastern HSC Trust.
5	Specific nursing, physiotherapy and appropriately shared roles within the team in the South Eastern HSC Trust need clear definition.
6	In the South Eastern HSC Trust criteria should be developed for people with complex respiratory disease to ensure referrals to the most appropriate community team.
7	The South Eastern HSC Trust should nominate a medical lead for NIV to support the community respiratory team.
8	The South Eastern HSC Trust should review the accommodation requirements for the community respiratory team.

Southern HSC Trust

9	The Southern ICP bid should be submitted as soon as possible for the HOSAR service in the Southern HSC Trust.
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Western HSC Trust

10	The Western HSC Trust should ensure the plan to restructure the three community teams into one specialist community respiratory team is implemented without delay.
11	Clinical leadership at an appropriate level should be developed for the specialist community respiratory team in the Western HSC Trust.
12	Specialist respiratory physiotherapy provision should be integrated into the specialist community respiratory teams in the Western HSC Trust.

Glossary

Asthma is a common condition that affects the airways - the small tubes that carry air in and out of the lungs. It causes a narrowing of these airways and this makes breathing more difficult. Patients may have wheezy episodes and quickly become out of breath.

Bronchiectasis is a relatively rare condition that affects the lungs. The bronchial tubes become enlarged and distended forming pockets where infection may gather. The walls become damaged which results in impairment to the lung's complex cleaning system. When this cleaning system is not working effectively dust, mucus and bacteria accumulate, infection develops and is difficult to remove.

Chronic refers to something bad (disease / condition) which is likely to continue for a long time.

Chronic Obstructive Pulmonary Disease (COPD) is the name given to a condition where people cannot breathe in and out properly because of long-term damage to the lungs. In COPD, the airways have become blocked ('obstructed') to some extent, and the air sacs may have become damaged. Causes of the blockage include an increased amount of mucus in the airways and narrowing of the passages as a result of the airway walls becoming thickened.

Continuous Positive Airways Pressure (CPAP) Patients wear a special nose or face mask at night that is connected to an airflow generator. The increased air pressure keeps the airway open and those with sleep apnoea can get the quality sleep they need.

Domiciliary oxygen is prescribed for patients in the home after careful evaluation.

Emphysema is the damage to the lung tissue in COPD that affects the ability of the air sacs to transfer air into the body and that makes the airways floppy.

Exacerbation is the worsening or flare-up of a condition.

Interstitial lung disease (ILD), refers to a group of lung diseases affecting the interstitium (the tissue and space around the air sacs of the lungs).

Kyphoscoliosis describes an abnormal curvature of the spine in both a coronal and sagittal plane. It is a combination of kyphosis and scoliosis. Kyphoscoliosis is a musculoskeletal disorder causing chronic underventilation of the lungs and may be one of the major causes of pulmonary hypertension. Oxygen on long-term may be necessary in patients with significant hypoxemia.

Multidisciplinary teams are made up of people from different areas of Study / expertise.

Non-invasive ventilation (NIV) is a method of helping a person to breathe artificially. The person wears a mask that covers the nose (or less commonly, a full face mask that covers the nose and mouth). This is connected to a small machine that pushes air through the mask and into the person's lungs.

Palliative care is care that aims to achieve the best quality of life possible for the patient and their family through active identification, holistic assessment and appropriate management of problems, when progressive advanced disease is not responsive to curative treatment.

Pneumonia is a serious illness in which one or both lungs become red and swollen and filled with liquid. People who are bedridden can easily get pneumonia.

Pulmonary Rehabilitation is a programme of care and activities co-ordinated by different types of healthcare professionals who work as a team to help you live as normal a life as possible. The programme should be designed specifically for the individual, with their full involvement. It should include exercises, information, diet and other ways of dealing with COPD.

Obstructive Sleep Apnoea means pauses in breathing during sleep. The airway becomes blocked and breathing stops repeatedly during sleep. Impulses from the brain then arouse the person enough to restart breathing but not enough that the person is fully awake. This cycle repeats hundreds of times during sleep and results in sleep deprivation. In severe cases, periods of not breathing may last for 60 to 90 seconds and may recur up to 500 times a night.

OSAHS Obstructive sleep apnoea hypopnea syndrome (see above). Hypopnea is defined as reduction in ventilation of at least 50 per cent that results in a decrease in arterial saturation of four per cent or more due to partial airway obstruction.

Oncology is the study and treatment of tumours (masses of diseased cells) in the body.

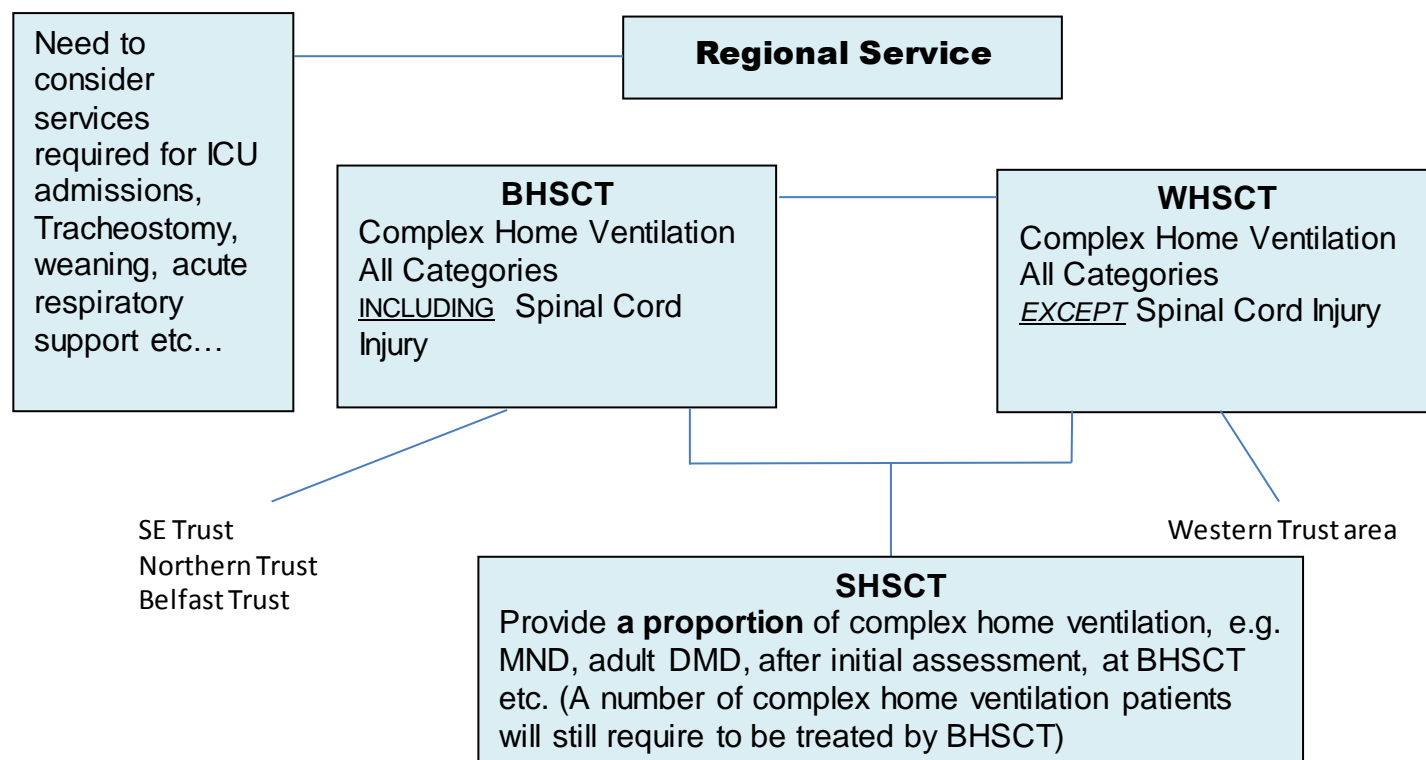
Spirometry a breathing test used to diagnose COPD and to monitor any changes in lung function over time.

Tertiary Care means treatment or care delivered and/or co-ordinated by health and social care staff in a specialist centre such as a regional centre attached to a major hospital. An example, is the regional cystic fibrosis centre.

Appendix A: Complex Home Ventilation in Northern Ireland July 2014

8. Proposed Model of Service

8.1 – Tertiary Service Model



Outpatient or day case multidisciplinary assessment and outreach will be provided at regional specialist centres for the following groups of patients:

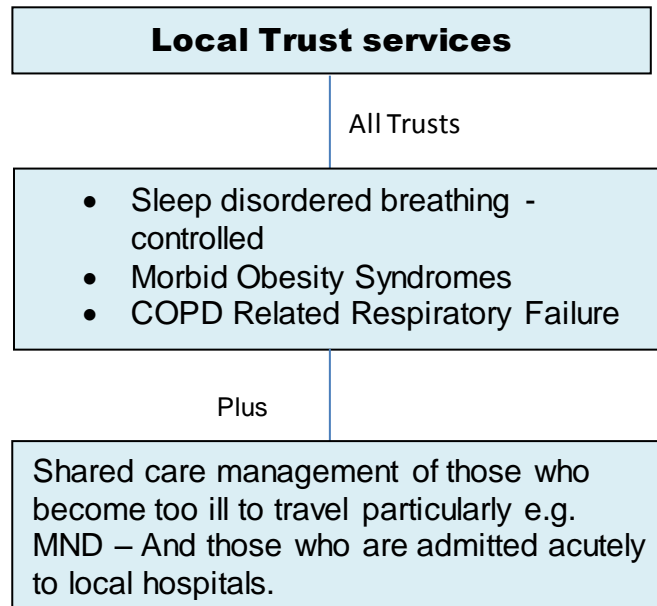
- Tracheostomy ventilated
- >14 hours/day non-invasive ventilator dependent
- Kyphoscoliosis
- Diaphragm pacing
- Patients with sub-optimal control of sleep disordered breathing – not responding
- Paediatric patients
- Those transitioning from paediatric services
- Spinal injuries, Kyphoscoliosis, Neuromuscular disease, Cardiomyopathy
- Inadequate initial clinical response to NIV trial
- Those requiring non-standard model of ventilation (negative invasive, volume targeted)
- Significant problems related to NIV e.g. pneumothorax

- People with MND should be referred to tertiary services (BHSCT and WHSCT) to start NIV on a planned basis. Subsequent follow up should be as per shared care guidelines, where appropriate.

8.2 – Recommendations to support tertiary service model

- Regional teams should have respiratory consultant input, respiratory nurse specialists, respiratory physiotherapist and respiratory physiology with specialist expertise.
- Within the BHSCT there is a requirement to provide two consultant sessions per week for new and review patients. There is a requirement for 1 additional wte nurse and 1 wte physiotherapist to provide input to starting NIV, review clinics and outreach for shared care and tertiary needs.
- Within the BHSCT, all elective referrals for NIV should be made to the BCH. The RVH will continue to start NIV on inpatients. Follow up arrangements will be determined by the service.
- All children and adolescents who require transition should be referred to the BCH within the BHSCT or to the service in the WHSCT.
- Pathways for transition between paediatric and adult services should be developed.
- Belfast Trust should be asked to develop a one stop shop service between neurology and respiratory services on the BCH site to facilitate shared care, co-ordinated management, improved patient/carer access and proper transition arrangements.
- Within the WHSCT there is a requirement for increased specialised respiratory nurse input for tertiary referrals.
- People with complex home ventilation needs within the SHSCT area will be supported by outreach from BHSCT.
- The current arrangements for referral to ICUs; management within and support to local centres; availability of weaning facilities and discharge arrangements need to be reviewed.

8.3 – Local Service Model



8.4 – Recommendations to support local service model

- Each local unit should have a consultant, respiratory nurse specialist and respiratory physiotherapist with a specialist interest in inpatient and community NIV. This team should maintain links with regional centres as agreed via shared care guidelines. It should also have sufficient respiratory physiology support.
- Availability of staff and expertise in each Trust needs to be reviewed and enhanced, particularly within the community.
- Local and regional registers should be maintained and cross referenced.
- Shared care and interface guidelines need to be developed.

8.5 – Recommendations for Equipment provision and funding

- For NIV each Health & Social Care Trust area should fund the rental of equipment for all patients resident within its area, regardless of whether community NIV has been started by the regional or local service. A mechanism should be set up in each trust area to allow rapid communication of need and setup.

- Each Trust should set up a database of patients, resident within its area, who are receiving community NIV. This should be cross-referenced with the BHSCT, SHSCT and WHSCT databases on a regular basis to ensure coordination and avoid duplication of equipment provision.

- Funding mechanisms need to be developed for cough assist devices to be more available, particularly in short time scales for conditions such as MND.

- Funding mechanisms need to be developed to allow for regional procurement of equipment, which is the most cost effective way to provide this equipment. A regional group should be set up, in conjunction with BSO procurement, led by BHSCT, and ensuring LCG membership, to consider taking regional procurement forward.



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