Department of
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and Public Safety
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REVISED SERVICE FRAMEWORK FOR RESPIRATORY HEALTH AND WELLBEING

CONSULTATION DOCUMENT

Working for a Healthier People

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Service Framework for Respiratory Health and Wellbeing

Summary of Standards

Communication and Involvement

	Key Performance Indicators	Anticipated Performance Level
Standard 1 (Generic) All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.	Percentage of patients and clients expressing satisfaction with communication.	March 2014 – Establish baseline and set target March 2015 – Report percentage increase of patient and client satisfaction with communication March 2016 – Report percentage increase of patient and client satisfaction with communication
Standard 2 (Generic) All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.	Percentage of job descriptions containing PPI as responsibility: • Year 1: senior and middle management • Year 2: designated PPI leads at all levels of HSC organisations • Year 3: all new job descriptions	March 2014 – Establish baseline and set target March 2015 – Monitor progress March 2016 – 100% - in all new job descriptions

	Percentage of patients and clients expressing satisfaction.	March 2014 – Establish baseline and set target March 2015 – Report percentage increase of patient and client satisfaction March 2016 – Report percentage increase of patient and client satisfaction
	Percentage of staff who have gained PPI training (details to be agreed for 2014/2015).	March 2014 – Conduct training needs assessment for PPI, commission design of PPI training programme March 2015 – Establish baseline and set target March 2016 – Monitor percentage of staff trained at different levels in PPI
Standard 3 (Generic) Users of Health and Social Care services and their carers should have access to independent advocacy as required.	To be determined	To be determined

Standard 4 (Generic) All Health and Social Care staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.	Number of front line staff in a range of settings participating in Carer Awareness Training Programmes. The number of carers who are offered Carers Assessments. The percentage of carers who participate in Carers Assessments.	March 2015 - 20% March 2016 - 50% Reviewed annually - Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group Reviewed annually - Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group

Health Improvement / Protection

	Key Performance Indicators	Anticipated Performance Level
Standard 5 (Generic) All Health and Social Care staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.	Percentage of people eating the recommended 5 portions of fruit or vegetables each day.	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females Target: maintain or at best increase percentage by 1% year on year
Standard 6 (Generic) All Health and Social Care staff, as appropriate, should provide support and advice recommended levels of physical activity.	Percentage of people meeting the recommended level of physical activity per week.	New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov / Dec 2013. Performance level to be agreed thereafter

Standard 7 (Generic) All Health and Social Care staff, as appropriate, should advise people who smoke of the risks associated with smoking and sign-post them to well-developed specialist smoking cessation services.	Number of people who are accessing Stop Smoking Services. Proportion of the smoking population who are accessing Stop Smoking Services. Number of people using stop smoking services who have quit at 4 weeks and 52 weeks.	Baseline 2011/12 = 39204. March 2014 -16 - 4 % year on year increase Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target to maintain at >/= 5% Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. Target 2% increase in respective numbers year on year
Standard 8 (Generic) All Health and Social Care staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.	Percentage of people who receive screening in primary care settings in relation to their alcohol consumption.	March 2014 - Establish baseline Performance level to be determined once baseline established

Standard 9 (Generic) All Health and Social Care staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.	All HSC Organisations and organisations providing services on behalf of the HSC have a Safeguarding Policy in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc). The Safeguarding Policy is supported by robust procedures and guidelines.	March 2014 - Establish baseline Performance level to be determined once baseline established
	All HSC Organisations and organisations providing services on behalf of the HSC have Safeguarding Plans in place.	March 2014 - Establish baseline Performance level to be determined once baseline established
	All HSC Organisations and organisations providing services on behalf of the HSC have safeguarding champions in place to promote awareness of safeguarding issues in their workplace.	March 2014 - Establish baseline Performance level to be determined once baseline established

Chronic Obstructive Pulmonary Disease (COPD)

	Key Performance Indicators	**Anticipated Performance Level**
Standard 10 All people suspected of having COPD should have accurate early diagnosis, assessment and management in primary care.	Percentage of GP practices that develop a register of people who are smokers and/or ex-smokers, over 35 and on short acting beta agonists to facilitate case finding for COPD.	March 2017 – All practices to have developed registers
	Percentage of people with COPD (diagnosed on or after 1 April 2011) in whom the diagnosis has been confirmed by post bronchodilator spirometry between 3 months before and 15 months after entering on to the register.	March 2016 – 60% March 2017 – 80%
	Percentage of people with COPD with a record of FEV_1 in the preceding 15 months.	March 2017 – 75%
	Percentage of people with COPD who have had a review, undertaken by a healthcare professional, including an assessment of breathlessness using the Medical Research Council dyspnoea scale in the preceding 15 months.	March 2016 – 70% March 2017 – 90%

	Percentage of people with a diagnosis of COPD and an MRC breathlessness score of >3 and/or functional breathlessness who have been referred for pulmonary rehabilitation.	March 2017 – 70%
	Percentage of people with COPD and Medical Research Council dyspnoea grade greater/equal to 3 at any time in the preceding 12 months, with a record of oxygen saturations value within the preceding 15 months.	March 2016 – 70% March 2017 – 90%
	Percentage of people with COPD with Sp02 levels <92% who are referred to the local Home Oxygen Assessment and Review (HOS-AR) service.	March 2017 – 90%
	Percentage of people with COPD who smoke, who have had appropriate smoking advice.	March 2016 – 90% March 2017 – 95%
	Percentage of people with COPD who have had influenza immunisation in the preceding 1 September to 31 March.	March 2016 – 95%

Standard 11 All people with COPD who meet the referral criteria should have access to the services provided by specialist respiratory teams in the community.	Percentage of people with severe/very severe COPD who are under the care of the Specialist Community Respiratory Team.	March 2017 – Establish baseline March 2018 – Performance levels to be agreed after
Standard 12 All people with COPD and their carers should be given the opportunity to learn about their disease. Those meeting the criteria for pulmonary rehabilitation and case management should receive enhanced supported self-management as part of their care.	Percentage of people with COPD given individualised, face to face information and a written self-management action plan. Percentage of people attending pulmonary rehabilitation programmes who have received individualised, face-to-face information and an updated written self-management action plan. Percentage of people with COPD receiving case management from specialist community respiratory teams who have received individualised, face-to-face information and an updated written self-management action plan.	March 2016 – 90% March 2018 – 95% March 2016 – 70% March 2018 – 90% March 2016 – 70% March 2018 – 90%

Standard 13 All people with an acute exacerbation of COPD should be managed to an optimal standard in an appropriate setting.	Percentage of GP practices with a red flag system to identify people presenting with an acute exacerbation of COPD in GP practices, OoH, emergency departments or ambulatory care settings.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of people with an acute exacerbation of COPD presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode by the GP, practice nurse, community or secondary care.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of people with COPD admitted to hospital for more than 24 hours with an exacerbation who receive care from a respiratory team.	March 2016 – 70% March 2017 – 90%
	Percentage of people managed in a respiratory ward or formally designated respiratory area within a ward.	March 2016 – 50% March 2018 – 70%

	Smoking status should be documented on all people admitted with an exacerbation of COPD and advice on smoking cessation offered and documented.	March 2016 – 70% March 2018 – 90%
Standard 14 All people with COPD with acute and/or chronic type 2 respiratory failure should have timely access to ventilatory support, if required, in a unit supervised by a respiratory physician or intensive care physician.	Percentage of people admitted with an exacerbation of COPD who have had an arterial blood gas (ABG) assessment on admission to identify ventilatory failure.	March 2016 – 90% March 2018 – 95%
	Percentage of people who receive non-invasive ventilation in a respiratory ward or dedicated formally designated respiratory area within a ward.	March 2016 – 90% March 2018 – 95%
	Percentage of people who receive non-invasive ventilation who have a clear management plan which includes ceiling of care.	March 2016 – 90% March 2018 – 95%

Standard 15 All people admitted to hospital with acute exacerbations of COPD should receive appropriate discharge planning and follow-up.	Percentage of people discharged from hospital following admission for an exacerbation of COPD who have the following aspects of the COPD discharge bundle completed: • smoking cessation advice • individualised self-management plan • inhaler technique checked • referral to pulmonary rehabilitation • referral to community team for assessment and review for more complex needs	March 2016 – 70% March 2018 – 90%
	Percentage of people discharged from hospital following admission for an exacerbation of COPD who have been offered access to rapid pulmonary rehabilitation within 4 weeks of discharge (providing they fulfil the inclusion criteria).	March 2016 – 40% March 2017 – 60%

Oxygen Therapy in COPD

	Key Performance Indicators	Anticipated Performance Level
Standard 16 All people requiring long term oxygen therapy (LTOT) are appropriately assessed prior to commencement of therapy.	Percentage of Trusts that have HOS-AR assessment processes in place for LTOT. Percentage of people started on LTOT who have been appropriately assessed via the assessment process.	March 2016 – All Trusts March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
Standard 17 Ambulatory oxygen therapy should be prescribed for all people already on LTOT who wish to continue with oxygen therapy outside the home, and who are prepared to use it, but only after an appropriate assessment has been performed by a specialist.	Percentage of Trusts that have HOS-AR assessment processes in place for ambulatory oxygen. Percentage of people prescribed ambulatory oxygen in addition to LTOT via a concentrator following specialist assessment.	March 2016 – All Trusts March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed

Standard 18 All people commenced on long term oxygen therapy have their condition reviewed at least annually by a specialist oxygen service (HOS-AR).	Percentage of people on LTOT who have had their condition reviewed by a specialist HOS-AR service in the last 12 months.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
Standard 19 All people with COPD should be treated with appropriate controlled oxygen therapy during transportation in ambulances.	Percentage of people with a history of hypercapnic respiratory failure issued with an Oxygen Alert Card and a 24% or 28% Venturi mask and Ambulance Control informed.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed

Asthma in Adults

	Key Performance Indicators	**Anticipated Performance Level**
Standard 20 All people with suspected asthma should have assessment and investigations to confirm the diagnosis.	Percentage of people aged 8 or over with asthma (diagnosed on or after 1 April 2006) on the register with measures of variability or reversibility recorded between 3 months before or any time after diagnosis.	March 2016 – 80%

Standard 21 All people with asthma and their carers should be given the opportunity to learn about their condition and receive a written individualised self-management asthma action plan.	Percentage of people with asthma step 2 and above who have had individualised face to face information and written self-management action planning. Number of people aged over 15 with newly diagnosed asthma step 2 or above, who have attended and completed an asthma specific structured education programme.	March 2016 – 80% March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
Standard 22 All people with asthma should be on appropriate pharmacological therapy according to the nature and severity of their disease.	Percentage of people with asthma, on the register, who have had an asthma review in the preceding 15 months that includes an assessment of asthma control using the 3 RCP questions. Percentage of people on step 5 treatment currently under the care of secondary care asthma services.	March 2016 – 70% March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed

Standard 23 All people with acute severe asthma should be accurately assessed and managed appropriately according to the severity of their presentation.	Percentage of people with acute severe asthma presenting to ED or OoH* who have a post bronchodilator PFR carried out. **only those people requiring to be nebulised in OoH*	ED March 2016 – 70% March 2017 – 80% OoH March 2016 – 40% March 2017 – 50%
	Percentage of people presenting with acute severe asthma to ED or OoH* who have an oxygen saturation of less than 94% who have a post bronchodilator oxygen saturation carried out and result recorded. **only those people requiring to be nebulised in OoH*	ED March 2016 – 60% March 2017 – 80% OoH March 2016 – 60% March 2017 – 80%
	Percentage of GP practices with a red flag system to identify people presenting with acute severe asthma in GP practices, OoH, emergency departments or ambulatory care settings.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed

	Percentage of people with acute severe asthma presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode by the GP, practice nurse, community or secondary care.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of practices with a register of people at risk of near fatal asthma.	March 2017 – 70%
	Percentage of people with acute severe asthma who are managed in a respiratory ward or formally designated respiratory area within a ward.	March 2016 – 80% March 2018 – 90%
	Percentage of people with acute severe asthma admitted to hospital with an exacerbation who received care from a respiratory team.	March 2016 – 60% March 2018 – 80%
	Percentage of people admitted with acute severe asthma on beta-2-agonist therapy only who are commenced on inhaled corticosteroids.	March 2016 – 80% March 2018 – 90%
	Percentage of people admitted with acute severe asthma who receive a written discharge care plan.	March 2016 – 60% March 2018 – 80%

Standard 24 All people with ‘difficult asthma’* should be assessed and managed by a team with the appropriate skills and experience. *’Difficult asthma’ is defined as those who are symptomatic on BTS/SIGN guidelines step 4 treatment and all people on step 5 treatment.	Percentage of people assessed to benefit from appropriate monoclonal antibody therapy who are offered a therapeutic trial.	March 2017 – 100%

Asthma in Children and Young People

	Key Performance Indicators	Anticipated Performance Levels
Standard 25 All children and young people with suspected asthma should have assessment and investigations to confirm the diagnosis.	Percentage of children and young people aged 8 or over with asthma (diagnosed on or after 1 April 2006) on the register with measures of variability or reversibility recorded between 3 months before or any time after diagnosis.	March 2016 – 80%

Standard 26 All children and young people with asthma and their carers should be given the opportunity to learn about their condition and receive a written individualised self-management asthma action plan.	Percentage of children and young people with asthma step 2 and above who have had individualised face to face information and written self-management action planning.	March 2016 – 80%
	Percentage of children and young people (under 14) with a diagnosis of asthma that attended and have been asked to demonstrate their inhaler technique at asthma review.	March 2016 – 80%
	Percentage of schools supported with policies and training for asthma.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
	Percentage of young people with asthma aged 14 or over and who have not attained the age of 20, on the register, in whom there is a record of smoking status in the preceding 15 months.	March 2016 – 80%

Standard 27		
All children and young people with acute severe asthma should be accurately assessed and managed appropriately according to the severity of their presentation.	Percentage of children / young people presenting with acute severe asthma to ED or OoH* who have an oxygen saturation 94% or less, who have a post bronchodilator oxygen saturation carried out and result recorded (if remains less than 92%, person should be admitted). **only those requiring to be nebulised in OoH*	ED March 2016 – 60% March 2017 – 80% OoH March 2016 – 60% March 2017 – 80%
	Percentage of GP practices with a red flag system to identify children / young people presenting with acute severe asthma within the previous 12 months in GP practices, OoH, emergency departments or ambulatory care settings.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of children / young people with acute severe asthma presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode by the GP, practice nurse, community or secondary care.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of children and young people with acute severe asthma who attend emergency	March 2016 – Baseline to be determined

	departments, ambulatory departments or are admitted, who are reviewed (by telephone or face-to-face) by an asthma specialist paediatric nurse within 14 days.	March 2017 – Performance indicators to be agreed
Standard 28 No child or young person should have a second unmanaged anaphylactic event.	Percentage of children younger than 16 years who have had emergency treatment for suspected anaphylaxis who are admitted to hospital under the care of a paediatric medical team.	March 2016 – 100%
	Percentage of children / young people who are referred to a specialist allergy service within 2 weeks of the primary episode (age-appropriate where possible) after emergency treatment for suspected anaphylaxis.	March 2017 – 100%
	Percentage of children / young people who are routinely prescribed an adrenalin auto-injector device who have not had the diagnosis confirmed at a specialist allergy service.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
	Percentage of schools attending an annual update on the recognition and treatment of acute anaphylaxis.	March 2016 – Baseline to be determined March 2017 – Performance

	Percentage of specialist staff within the asthma and allergy service that have had training in the management of emotional, social and psychological issues of children and young people with severe generalised allergic and anaphylactic reaction. Percentage of Trusts who have developed pathways for emotional, social and psychological support for children with severe generalised allergic reactions and anaphylaxis, as set out in the emotional, social and psychological support section of this service framework.	indicators to be agreed March 2016 – 50% March 2017 – 60% March 2017 – All Trusts
Standard 29 All children / young people with 'difficult asthma'* should be assessed and managed by a team with the appropriate skills and experience.	Percentage of children and young people on beclometasone dipropionate or budesonide 800 mg/day (or fluticasone propionate 400 mcg/day) who have been given a steroid alert card.	March 2016 – 90%

	Percentage of children and young people attending outpatients who have had appropriate management as per BTS guidelines.	March 2016 – 90% for each criterion
	Percentage of children and young people who are admitted, who have appropriate inpatient and discharge planning as per BTS guidelines.	March 2016 – 40% March 2017 – 60% March 2018 – 80% for each criterion
	Percentage of children and young people with difficult to treat asthma who do not respond to treatment attending a secondary care service, who have a home visit from a specialist respiratory nurse.	March 2016 – 40% March 2017 – 60% March 2018 – 80%
	Percentage of children and young people with difficult to treat asthma who do not respond to treatment attending the tertiary care service, who have a home visit from a specialist respiratory nurse.	March 2016 – 40% March 2017 – 60% March 2018 – 80%
	Percentage of specialist staff within the asthma and allergy service that have had training in the management of emotional, social and psychological issues of children and young people with difficult asthma.	March 2016 – 50% March 2017 – 90%

	Percentage of Trusts who have developed pathways for emotional, social and psychological support for children with difficult asthma, as set out in the emotional, social and psychological support section of this service framework.	March 2017 – All Trusts

Community Acquired Pneumonia in Adults

	Key Performance Indicators	Anticipated Performance Level
Standard 30 All people with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to BTS pneumonia guidelines.	Percentage of people admitted to hospital with suspected CAP who have a chest x-ray performed and reviewed before being commenced on antibiotic therapy for CAP.	March 16 – 80% March 17 – 90%
	Percentage of people with CAP in whom diagnosis is confirmed by chest radiograph and first antibiotic dose administered within 4 hours from admission*.	March 16 – 80% March 18 – 90%
	Percentage of people diagnosed with CAP who receive antibiotics in line with trust guidance *(appropriateness should be verified by antimicrobial pharmacist and microbiologist).*	March 16 – 80% March 18 – 90%

	Percentage of people diagnosed with CAP who are reviewed by a consultant within 24 hours of admission*. **time of admission refers to the presentation time at the hospital (ambulance transfer sheet/time recorded in notes) if this is available.*	March 16 – 90% March 18 – 95%

Community Acquired Pneumonia in Children and Young People

	Key Performance Indicators	**Anticipated Performance Level**
Standard 31 All children and young people with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to the BTS Guidelines.	Percentage of children and young adults diagnosed with CAP who are appropriately investigated and managed as per BTS guidelines in the following key areas: • Chest x-ray (assessment and post discharge) • Routine blood tests • Antibiotic therapy • Oral versus IV antibiotics • Post-discharge follow-up in secondary care	March 2016 – 75% and 6-monthly thereafter March 2018 – 90%

	Percentage of children and young people with CAP transferred from another hospital to a ward in RBHSC who are admitted to PICU within 24 hours of arrival in RBHSC.	March 2016 – 20% March 2017 – 10%
	Percentage of children and young people requiring admission to PICU with CAP who are admitted within 6 hours of decision to admit.	March 2016 – 80% March 2017 – 90%

Obstructive Sleep Apnoea/Hypopnoea Syndrome (OSAHS) in Adults

	Key Performance Indicators	**Anticipated Performance Level**
Standard 32 All adults with a clinical suspicion of having obstructive sleep apnoea / hypopnoea syndrome (OSAHS), should have investigation (ie. overnight oximetry and/or limited polysomnography) at a specialist OSAHS service in their local Health and Social Care Trust led by a respiratory physician.	Percentage of Trusts that have specialist OSAHS services which can provide overnight oximetry; limited polysomnography and CPAP provision. Percentage of people with suspected severe OSAHS, or those working in safety critical occupations, who have been assessed and investigated within 6 weeks.	March 2017 – All HSC Trusts March 2017 – 50% March 2018 – 80%

	Percentage of people with lower risk OSAHS who are assessed (currently 9 weeks) and treated (currently 13 weeks), as per DHSSPS waiting time targets.	March 2017 – 50% March 2018 – 80%
Standard 33 All people with suspected OSAHS, and where a limited sleep study is negative or inconclusive in the setting of high clinical suspicion, should have timely and appropriate access to inpatient full polysomnography (PSG) in the regional respiratory centre.	Regional respiratory centre (at BCH) should establish a regional OSAHS service for people requiring full polysomnography. Percentage of people with normal limited sleep studies in whom OSAHS is still suspected, who have had an overnight inpatient full PSG.	March 2016 – Service established March 2017 – 60% March 2018 – 80%
Standard 34 All people with OSAHS should be provided with information on lifestyle modification and referred to services as appropriate.	Percentage of Trusts who have established a system to ensure that all people have the lifestyle assessment proforma completed, appropriate advice given and appropriate referral offered.	March 2016 – All Trusts

	Percentage of Trusts who have processes in place to ensure that all members of MDT (medical, nursing and respiratory physiologists) have had training in brief intervention in smoking and alcohol, and weight management and behavior modification techniques.	March 2016 – 80% March 2017 – 90%
Standard 35 All people should have timely and equitable access to CPAP treatment, regular review and follow up at Trust level by dedicated CPAP respiratory physiologists / respiratory nurse specialists.	Percentage of people meeting urgent referral criteria who have commenced CPAP within 4 weeks. Percentage of people on CPAP who were treated as per the regionally agreed pathway (confirmed with sleep study 4-6wks post initiation and clinical review). Percentage of people who were reviewed on an annual basis with CPAP adherence checked.	March 2016 – 95% March 2017 – 80% March 2017 – 40% March 2018 – 60%

Obstructive Sleep Apnoea Syndrome In Children And Young People

	Key Performance Indicators	**Anticipated Performance Level**
Standard 36 All children and young people with obstructive sleep apnoea syndrome should have the condition accurately assessed for severity and treated in a timely fashion.	All trusts should have a nominated clinician(s) who is be able to initiate and interpret investigation (e.g. oximetry) for suspected OSAS and make appropriate referrals (e.g. to ENT) of children with abnormal studies.	March 2016 – 100%
	Percentage of children and young people with OSASH failing first line treatments who are deemed suitable for CPAP, who obtain access to appropriate equipment (with backup technical and equipment support) and training in its use within 2 weeks and 9 weeks, depending on level of urgency.	March 2016 – 95%
	Percentage of children and young people with a diagnosis of OSAHS who have a named link respiratory nurse to access the multidisciplinary team at RBHSC.	March 2016 – 95%

Long Term Ventilation in Adults

	Key Performance Indicators	**Anticipated Performance Level**
Standard 37 All adults requiring, or potentially requiring long term ventilation, should have access to services that improve survival, enhance quality of life, avoid unplanned admissions to hospital and support their choice of end of life care.	Percentage of people who are at risk of neuromuscular respiratory failure, who have an annual forced vital capacity (FVC) or equivalent (mouth or nasal pressures) and symptom check for neuromuscular respiratory failure and SpO_2 measurement.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed
	Percentage of people with motor neurone disease who have a 3-monthly assessment of forced vital capacity (FVC) or equivalent (mouth or nasal pressures) and symptom check for neuromuscular respiratory failure and SpO_2 measurement within the first 24 months of diagnosis (unless already on NIV).	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of people with symptoms of neuromuscular respiratory failure or with FVC <50% (or inspiratory pressure <40 cm water) sitting or lying, who are assessed and reviewed by a regional specialist multidisciplinary team (neurological and respiratory: medical, nursing & physiotherapy) every 6 months.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed

	Percentage of people with complex needs on community long term ventilation who have access to support from a tertiary centre specialist respiratory nurse with expertise.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of people with complex needs on community long term ventilation who have access to support from a tertiary centre specialist respiratory physiotherapist with expertise.	March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed
	Percentage of Trusts with named leads (respiratory physician, specialist respiratory nurse and specialist respiratory physiotherapist) to provide shared care support to people during acute admissions and for those who are unable to travel to regional services.	March 2016 – All Trusts
	Percentage of Trusts with named leads (respiratory physician, specialist respiratory nurse and specialist respiratory physiotherapist) to provide support across acute and community for people with COPD and OSAHS and obesity hypoventilation syndrome.	March 2016 – All Trusts
	Percentage of people who require cough augmentation equipment, who access it at time of discharge from hospital or within 4 months of decision to provide when	March 2016 – Baseline to be determined March 2017 – Performance

	being managed in the community. Percentage of people with motor neurone disease who require cough augmentation equipment, who access it within 2 weeks of decision of clinical need. Percentage of people with symptomatic neuromuscular respiratory failure who have had the following (according to stage of illness): • Communication about prognosis • Shared decision making on ceilings of care • Advance care planning • Discussion on preferred place of care	indicators to be agreed March 2017 – 50% March 2018 – 70% March 2017 – Baseline to be determined March 2018 – Performance indicators to be agreed

Long Term Ventilation in Children and Young People

	Key Performance Indicators	**Anticipated Performance Level**
Standard 38 All children and young people requiring or potentially requiring long term ventilation (LTV) or nocturnal non-invasive ventilatory (NNIV) support at home should have access to a specialist multidisciplinary team at tertiary level.	Percentage of children and young people requiring NNIV/LTV who receive an initial assessment / management (within 4 weeks) and regular follow up (at least twice yearly) by the specialist regional multidisciplinary team.	March 2016 – 80%
	Percentage of children and young people requiring inpatient sleep studies who are admitted within 13 weeks.	March 2016 – 60% March 2017 – 70% March 2018 – 100%
	Percentage of children and young people requiring long term ventilation where a decision has been made to discharge to home or step-down care who are discharged within 6 months.	March 2016 – 70% March 2017 – 80% March 2018 – 90%
	Percentage of children and young people starting ventilatory support and at critical periods who have specific play therapy input to support and optimise compliance.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed

	Percentage of children who require cough augmentation equipment, who access it within 4 months of decision to provide.	March 2016 – 50% March 2018 – 100%
	Percentage of children and young people whose initial and essential investigations and treatment, as part of evidence based pathways, are coordinated in clinically appropriate times.	March 2016 – 20% March 2017 – 40% March 2018 – 60%
	Percentage of children and young people who require psychology support who receive it from a nominated psychologist with an interest in respiratory disease, within 15 weeks.	March 2016 – Baseline to be determined March 2017 – Performance indicators to be agreed

Cystic Fibrosis

	Key Performance Indicators	**Anticipated Performance Level**
Standard 39 All newborn babies in Northern Ireland should be offered screening for cystic fibrosis.	Percentage of babies born in Northern Ireland (and still resident) with conclusive blood spot screening result recorded on Child Health System by 17 days of age.	March 2016 – 18 – UK Standard to be confirmed April 2014

Standard 40 All people suspected of having cystic fibrosis should have appropriate diagnostic testing at a specialist centre.	Percentage of babies suspected of having cystic fibrosis (2 mutations identified) should have their first clinical appointment with the cystic fibrosis team by 28 days of age. Percentage of babies suspected of having cystic fibrosis (1 mutation identified + second IRT positive OR no mutations identified + second IRT positive) should have their first clinical appointment with the cystic fibrosis team by 35 days of age.	March 2016 – 18 95% Acceptable 100% Achievable March 2016 – 18 80% Acceptable 100% Achievable
Standard 41 All people with cystic fibrosis should receive care from a specialist centre delivered by a specialist multidisciplinary team. Care should be in line with best practice guidelines.	Percentage of adults who have the following data recorded annually: • FEV_1 % predicted • BMI • Sputum microbiology Percentage of children who have the following data recorded annually: • BMI centile or weight centile for those <2	March 2017 – 90% March 2017 – 90%

	- Sputum microbiology Percentage of children >5 years old who can perform spirometry who have FEV1 % predicted recorded annually. Percentage of people reporting satisfaction with communication /information received from the specialist team.	March 2016 – 90% March 2016 – 90% (Adults and Children)
Standard 42 All people with cystic fibrosis should have their care provided in a safe environment consistent with infection control policies.	Percentage of people receiving microbiological surveillance of at least 4 samples (sputum or cough swab) per year. Percentage of inpatients in single room accommodation.	March 2017 – 85% March 2016 – 100%

Bronchiectasis

	Key Performance Indicators	Anticipated Performance Level
Standard 43 All people with suspected bronchiectasis should be investigated in line with BTS guidance.	**ADULTS** Percentage of people with clinical diagnosis of bronchiectasis that have had diagnosis confirmed by high resolution CT chest.	March 2016 – 90%
	Percentage of people with a clinical diagnosis of bronchiectasis who have been investigated for: • Allergic bronchopulmonary aspergillosis • Common variable immunodeficiency • Cystic fibrosis in up to all individuals <40 years old (and considered in >40 for those indicated by BTS guidance)	March 2016 – 40% March 2017 – 60%
	CHILDREN Percentage of children and young people with suspected bronchiectasis who have the appropriate investigations completed as per the BTS guidelines in tertiary care.	March 2016 – 80% of children meet the diagnostic criteria March 2018 – 100%

Standard 44 All people with clinically significant bronchiectasis should be accurately assessed and managed by a multidisciplinary respiratory team including a consultant, physiotherapist and nurse with a special interest in bronchiectasis.	**ADULTS - Stable** Number of trusts with access to a specialist respiratory team comprising at least a respiratory clinician, respiratory specialist nurse and a physiotherapist with a special interest in bronchiectasis.	March 2016 – All Trusts
	Percentage of individuals diagnosed with bronchiectasis that have been reviewed by a respiratory physiotherapist.	March 2016 – 90%
	Percentage of individuals with a diagnosis of bronchiectasis that had sputum bacteriology culture when clinically stable sent and recorded within the last 12 months.	March 2016 – 80%
	Percentage of people with breathlessness affecting activities of daily living referred to pulmonary rehabilitation.	March 2016 – 60% March 2018 – 80%
	ADULTS - Exacerbations Percentage of individuals with an exacerbation of bronchiectasis that have a sputum sample sent for microbiological culture prior to empirical treatment.	March 2016 – 80%

	Percentage of individuals with an exacerbation of bronchiectasis with an objective evaluation of efficacy (at least one of bacteriology, inflammatory markers or spirometry).	March 2016 – 80%
	Percentage of individuals with an exacerbation of bronchiectasis that are offered home IV therapy where appropriate.	March 2016 – 60% March 2018 – 80%
	CHILDREN TERTIARY CARE - Stable Percentage of children and young people with symptomatic disease who attend a one-stop-shop multidisciplinary service.	March 2016 – 100%
	Percentage of children and young people who have a comprehensive annual review to include spiromotery, BMI centile and sputum microbiology where appropriate.	March 2016 – 90%
	Percentage of children and young people who have regular microbiological surveillance every 3 months.	March 2016 – 60% March 2018 – 90%

	CHILDREN TERTIARY CARE - Exacerbations Percentage of children and young people with poorly controlled symptoms or exacerbations who are admitted within 72 hours of the decision to admit. Percentage of children and young people admitted with bronchiectasis for IV antibiotics that have therapy started within 24 hours of admission.	March 2016 – 100% March 2016 – 100%
Standard 45 All individuals with symptomatic bronchiectasis and their carers should be given the opportunity to learn about their disease and receive individualised self-management information.	Percentage of adults attending secondary care who have been given individualised, face-to-face information and a written action plan.	March 2016 – 60%

Interstitial Lung Disease (ILD)

	Key Performance Indicators	**Anticipated Performance Level**
Standard 46 People with known or suspected ILD should be under the care of a respiratory multidisciplinary team for interstitial lung disease.	Percentage of Trusts who have local access to a radiologist with expertise in thoracic imaging.	March 2017 – 100%
	Percentage of Trusts who have regional access to a pathology service with appropriate expertise in ILD.	March 2017 – 100%
	Percentage of Trusts with a named lead consultant respiratory physician with an interest in ILD.	March 2016 – 100%
	Percentage of Trusts with a named specialist respiratory nurse with an interest in ILD.	March 2017 – 100%
	Percentage of people with suspected ILD / IPF who have had case discussion at a local multidisciplinary team meeting for ILD.	March 2018 – 50%
	Percentage of people with ILD / IPF who have been assessed as per the evidence based pathway, at a regional centre for Pirfenidone and other novel therapies.	March 2018 – Establish baseline

Pulmonary Rehabilitation

	Key Performance Indicators	Anticipated Performance Level
Standard 47 All people with respiratory conditions who can benefit from pulmonary rehabilitation should be offered this by their GP or specialist respiratory team.	Percentage of people with COPD who meet the criteria for pulmonary rehabilitation and have been offered referral for pulmonary rehabilitation.	March 2017 – 50%
	Percentage of pulmonary rehabilitation programmes which are geographically accessible i.e. within 30 minutes of travel.	March 2016 – 100%
	Percentage of pulmonary rehabilitation programmes which include all required elements as per BTS guidelines.	March 2016 – 100%
	Percentage of pulmonary rehabilitation programmes which have a mechanism to provide support to people for on-going exercise and social support for those who need this.	March 2016 – 100%

Transitional Care for Adolescents with Chronic Respiratory Disease

	Key Performance Indicators	Anticipated Performance Level
Standard 48 All young people with chronic respiratory disease (difficult asthma / OSAS / LTV / cystic fibrosis / bronchiectasis) should have appropriate arrangements in place for transition for transfer to adult services.	Trust self-assessment against service specifications for transitional care arrangements for: *i) Difficult asthma* *ii) Cystic fibrosis* *iii) Bronchiectasis* *iv) LTV* *v) OSAS*	March 2017 – All Trusts should be able to meet service specifications

Acute Oxygen Therapy

	Key Performance Indicators	Anticipated Performance Level
Standard 49 All acutely ill people, apart from those at risk from hypercapnic respiratory failure, should have oxygen prescribed to achieve a normal or near normal oxygen saturation.	Emergency oxygen therapy should be prescribed using a target saturation range for people admitted to hospital requiring oxygen therapy.	March 2016 – 60% March 2017 – 80%

Social and Emotional Support

	Key Performance Indicators	Anticipated Performance Level
Standard 50 All people with severe respiratory disease and their carers should be offered an holistic assessment of their needs and be facilitated and supported to maintain their connections with social networks and community life, in order to promote wellbeing and mitigate the potentially isolating effects of long term disability.	Percentage of local areas with patient self-help support groups supported and facilitated by HSC Trusts (approximately 80,000 population).	March 2018 – 100%
	Percentage of local areas with generic expert patient programmes available for people with respiratory disease (approximately 80,000 population).	March 2018 – 100%
	Percentage of people on specialist community respiratory team caseloads who have had an holistic assessment and action planning of their social and emotional support needs.	March 2018 – 80%
	Percentage of local LCG areas with timely access to psychology services for those with severe anxiety and depression secondary to respiratory disease when other interventions are not sufficient, as per the emotional social and psychological support model.	March 2018 – 100%

	Percentage of people who have been offered to move on from pulmonary rehabilitation to local exercise/support groups. Percentage of carers (of people with respiratory disease who are on community team caseloads) who have been offered a formal carers assessment, where appropriate.	March 2018 – 80% March 2018 – 90%

Information

	Key Performance Indicators	**Anticipated Performance Level**
Standard 51 All patients, clients and carers should receive information which will allow them to know about general management options for their condition as well as the range of services available locally, including health promotion and appropriate community support services.	Percentage of local* areas where directories of services are available in a variety of formats written(*Approximately 150,000 population) Information available (including links to above) on HSCB and NI Direct websites. Percentage of people with respiratory disease accessing on-line support groups via HSC web and portal.	March 2017 – All areas March 2017 – All websites March 2016 – Establish baseline March 2017 – 10% increase on baseline

		March 2018 – 20% increase on baseline
	Percentage of carers of people with respiratory disease accessing on-line support groups via HSC web and portal.	March 2016 – Establish baseline March 2017 – 10% increase on baseline March 2018 – 20% increase on baseline

Training

	Key Performance Indicators	**Anticipated Performance Level**
Standard 52 All HSC staff, as relevant, should be appropriately trained to meet modern authoritative standards, and have the necessary knowledge, skills and competencies to provide respiratory services and manage respiratory conditions.	Percentage of GP employed nurses with completed self-assessment as per NIPEC R-CAT.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed
	Percentage of Trust employed specialist paediatric respiratory nurses with completed self-assessment as per NIPEC R-CAT.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed
	Percentage of Trust employed specialist adult respiratory nurses who have completed self-assessment as per NIPEC R-CAT.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed

	Percentage of Trust-employed specialist respiratory physiotherapists, carrying out pulmonary rehabilitation, who have been trained to the standards agreed by the regional respiratory forum.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed
	Percentage of GP practices who have a minimum of 1 registered nurse who has successfully completed a recognised post-graduate respiratory course in COPD, level to be agreed by GMS training group.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed
	Percentage of GP practices who have a minimum of 1 registered nurse who has successfully completed an approved post-graduate respiratory course in asthma, level to be agreed by the GMS training group.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed
	Percentage of GP practices who have a minimum of 1 registered nurse who has completed an approved spirometry training course*. **An approved spirometry course should cover theoretical aspects as well as practical aspects, and individuals should be trained to both conduct the test as well as interpreting the result.*	March 2016 – Establish baseline March 2017 – Performance levels to be agreed

	Percentage of GP practices where a primary care HSC professional has completed brief intervention training for smoking cessation. Percentage of Trust HSC professionals providing a respiratory service who have completed brief intervention training for smoking cessation.	March 2016 – Establish baseline March 2017 – Performance levels to be agreed March 2016 – Establish baseline March 2017 – Performance levels to be agreed

Medicines Management

	Key Performance Indicators	**Anticipated Performance Level**
Standard 53 In partnership with healthcare professionals, all people with respiratory disease should be provided with appropriate, safe and effective medicines and medicines information to enable them to gain maximum benefits from medicines to maintain or increase their quality and duration of life.	Percentage of respiratory prescribing in accordance with local medicines formulary. Percentage of people with respiratory conditions accessing a medicines management support service.	March 2016 – 70% March 2017 – 18 – On-going in tandem with development of the NI formulary March 2016 – Establish baseline March 2017 – Performance levels to be agreed

Standard 54 People with respiratory disease should have a systematic review of all their medicines at appropriate intervals along the care pathway to ensure that their medicines continue to be appropriate, and that they participate in the treatment as prescribed.	Percentage of people with respiratory disease in secondary care who have had their medicines list checked and verified as accurate on admission.	March 2017 – Establish baseline March 2018 – Performance levels to be agreed

Palliative Care

	Key Performance Indicators	Anticipated Performance Level
Standard 55 All people with advanced progressive incurable respiratory conditions should have their end of life care needs identified; co-ordinated care provided by a designated key worker, to meet these needs; and supported to die in their preferred place of care, in close collaboration with family and carers at all stages.	Percentage of people on community specialist team caseloads who have been assessed as to whether they have palliative care needs using Northern Ireland palliative care guidance (for COPD) or appropriate indicators of possible last year of life in Idiopathic Pulmonary Fibrosis. Percentage of people identified as being possibly in last year of life on community team caseloads who are recorded on the GP	March 2016 – 50% March 2018 – 90% March 2016 – 50% March 2018 – 90%

	palliative care register and discussed at the practice multi-disciplinary meeting.	
	Percentage of people with a respiratory diagnosis on the Trust palliative care database who have had an holistic assessment and a care plan developed (including carer needs).	March 2016 – 50% March 2018 – 90%
	Percentage of people with respiratory diagnosis on the Trust palliative care database with an identified named key worker (usually specialist respiratory team member coordinating with district nursing who then takes on key worker role in last few weeks) responsible for ensuring the 24 hour plan of care is communicated to relevant professionals.	March 2016 – 50% March 2018 – 90%
	Percentage of people with respiratory disease on the Trust palliative care database who are enabled to die in their appropriate preferred place of care (identified as part of regularly reviewed assessments).	March 2016 – 10% March 2018 – 30%
	Percentage of the specialist respiratory team members who have had training in appropriate	March 2016 – 80% March 2018 – 90%

	palliative care competencies. Percentage of specialist respiratory team members trained in appropriate communication skills.	March 2016 – 95%
Standard 56 (Generic) All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care.	Percentage of the population that is enabled to die in their preferred place of care. Percentage of population with a understanding of advance care planning psychosocial needs have appropriate input from specialist palliative care services for advice or management in accordance with the Regional Criteria for Specialist Palliative Care.	March 2014 – Establish baseline. Performance level to be agreed March 2014 – Establish baseline. Performance level to be agreed

SECTION 1 – INTRODUCTION

Background

The overall aim of the Department of Health, Social Services and Public Safety (DHSSPS) is to improve the health and social wellbeing of the people in Northern Ireland.

In support of this the Department has commenced the development of a range of Service Frameworks which set out explicit standards for health and social care that are evidence based and are capable of being measured.

The first round of service frameworks focussed on the most significant causes for ill health and disability - cardiovascular health and wellbeing, respiratory health and wellbeing, cancer prevention, treatment and care, mental health and wellbeing and learning disability. A Service Framework for older people has also recently been launched, while work is ongoing to develop a Service Framework for children and young people.

Service Frameworks have been identified as a major strand of the reform of health and social care services and provide an opportunity to:

- Strengthen the integration of health and social care services;
- Enhance health and social wellbeing, to include identification of those at risk, and prevent / protect individuals and local populations from harm and / or disease;
- Promote evidence-informed practice;
- Focus on safe and effective care; and,
- Enhance multidisciplinary and intersectoral working.

Aim of Service Frameworks

Service frameworks will set out the standards of care that patients, clients, their carers and wider family can expect to receive in order to help people to:

- prevent disease or harm;

- manage their own health and wellbeing including understanding how lifestyle affects health and wellbeing including the causes of ill health and its effective management;
- be aware of what types of treatment and care are available within health and social care;
- be clear about the standards of treatment and care they can expect to receive.

All Service Frameworks incorporate a specific set of standards that are identified as Generic. These, essentially, are intended to apply to all the population, or all HSC professionals or all service users, regardless of their health condition or social grouping. These include:

- communication (Generic standard 1);
- involvement (Generic standard 2);
- independent advocacy (Generic standard 3);
- carers (Generic standard 4);
- healthy eating (Generic standard 5);
- physical activity (Generic standard 6);
- smoking cessation (Generic standard 7);
- alcohol (Generic standard 8);
- safeguarding (Generic standard 9); and
- palliative care (Generic standard 56).

These Generic standards reinforce the holistic approach to health and social care improvement and reflect the importance of health promotion in preventing medical or social care issues occurring in the first place. Their inclusion ensures:

- equity of opportunity for all;
- the communication of consistent messages to service users and providers of HSC; and
- a consistent approach in the design and delivery of services.

Service Frameworks will also be used by a range of stakeholders including commissioners, statutory and non-statutory providers, and the Regulation and Quality Improvement Authority (RQIA) to commission services, measure performance and monitor care.

The Frameworks will identify clear and consistent standards informed by expert advice and by national standard setting bodies such as the National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE). The auditing and measuring of these standards will be assisted by the Guidelines and Implementation

Network (GAIN) which regional audit linked to priority areas, including Service Frameworks.

The standards, in the context of the 10 year Quality Strategy[1], will aim to ensure that health and social care services are:

i. **Safe** – health and social care which minimises risk and harm to service users and staff;

ii. **Effective** – health and social care that is informed by an evidence base (resulting in improved health and wellbeing outcomes for individuals and communities), is commissioned and delivered in an **efficient** manner (maximising resource use and avoiding waste), is **accessible** (is timely, geographically reasonable and provided in a setting where skills and resources are appropriate to need) and **equitable** (does not vary in quality because of personal characteristics such as age, gender, ethnicity, race, disability (physical disability, sensory impairment and learning disability), geographical location or socioeconomic status).

iii. **Person centred** – health and social care that gives due regard to the preferences and aspirations of those who use services, their family and carers and respects the culture of their communities. A person of any age should have the opportunity to give account of how they feel and be involved in choices and decisions about their care and treatment dependent on their capacity to make decisions. In absence of the capacity to make decisions they should listen to those who know and care for the person best.

Involving and communicating with the public

The Department has produced guidance, "Strengthening Personal and Public Involvement in Health and Social Services"[2], which sets out values and principles which all health and social care organisations and staff should adopt when engaging with the public and service users.

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[1] Quality 2020: A 10-Year Quality Strategy for Health and Social Care in Northern Ireland. Available from: http://www.dhsspsni.gov.uk/index/phealth/sqs/quality_strategy_2020.htm

[2] DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07). Available from: http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

These include the need to involve people at all stages in the planning and development of health and social care services. This policy position has been strengthened by the introduction of the Health and Social Care (Reform) Act (Northern Ireland) 2009 and the statutory duty it places on HSC organisations to involve and consult with the public. (Art 19)

It is important that the views of service users and carers are taken into account when planning and delivering health and social care. The integration of the views of service users, carers and local communities into all stages of the planning, development and review of Service Frameworks is an important part of the continuous quality improvement and the open culture which should be promoted in HSC.

Through the proactive involvement of the public in the planning of Service Frameworks, it is hoped that concerns and ideas for improvement can be shared and that the standards developed in partnership with service users, carers and the public will focus on the issues that really matter to them.

It is also important that Service Frameworks provide service users and carers with clear and concise information, which is sensitive to their needs and abilities, so that they can understand their own health and wellbeing needs. To facilitate this, easy access versions will be made available for all Service Frameworks. Service Frameworks will also be made available in various other formats e.g. Braille, large print and audio tape. The Department will also consider requests for other formats or translation into ethnic minority languages.

People are ultimately responsible for their own health and wellbeing and that of their dependents, and it is important that service users, their carers and wider family are made aware of the role they have to play in promoting health and wellbeing.

Involving other agencies in promoting health and wellbeing

Improving the health and wellbeing of the population requires action right across society and it is acknowledged that health and wellbeing is influenced by many other factors such as poverty, housing, education and employment. While Service Frameworks set standards for providers of health and social care services it is essential that HSC services work in partnership with other government departments and agencies both statutory and non-statutory to seek to influence and improve the health and social wellbeing of the people.

People who use health and social care services may have complex needs which require inputs from a range of health and social care professionals and other agencies.

The benefits of multidisciplinary team working and multiagency working, including voluntary and community organisations, are well recognised and it is a key component of decision making regarding prevention, diagnosis, treatment and ongoing care. This will be a key theme underpinning the development and implementation of Service Frameworks.

Data Collection

As Service Frameworks are implemented it is important that robust accurate data are available to support decision making and service improvement. Each specialist service must ensure timely submission of robust data collection to a regionally agreed minimum dataset. Where there are gaps in the availability of data against which to monitor service improvement then work should be undertaken at an early stage to develop these minimum datasets.

Research and Development

It is important that service frameworks are based on valid, relevant published research, where available, and other evidence.

Education and Workforce

Education and workforce development occur at individual, team, organisational, regional and national levels: they are part of the drive to promote quality. The ongoing development and implementation of Service Frameworks will influence the education and training agenda and curricula content for all staff involved in the delivery of health and social care. This will require a commitment to lifelong learning and personal development alongside a focus on specific skill areas to ensure that newly qualified and existing staff are in a position to deliver on quality services.

Leadership

Effective leadership is one of the key requirements for the implementation of Service Frameworks and will require health and social care professionals from primary, community and secondary care to work together across organisational boundaries, including the voluntary and community sectors. It is essential that Service Frameworks are given priority at senior, clinical and managerial level and implemented throughout all HSC organisations.

Affordability

Many of the standards contained in the Framework do not require additional resources as they are focussed on quality improvement and should be capable of delivery by optimising the use of existing funding. Where there are additional costs associated with specific standards, these will be sought through existing service development and commissioning processes; performance indicators and targets will be reviewed and adjusted as necessary in the light of the available resources in any one year.

SECTION 2 – SERVICE FRAMEWORK FOR RESPIRATORY HEALTH AND WELLBEING – BACKGROUND AND INTRODUCTION

Introduction

The aim of this framework is to improve the health and wellbeing of the population of Northern Ireland, reduce inequalities and improve the quality of health and social care in relation to respiratory disease, recognising that achievement of this aim goes beyond traditional HSC boundaries and is strongly influenced by population/individual attitudes and behaviours, and the contribution of other sectors.

The Service Framework for Respiratory Health and Wellbeing sets standards in relation to the prevention, assessment, diagnosis, treatment, care, rehabilitation and palliative care of individuals/communities who currently have or are at greater risk of developing respiratory disease. Recognising that several diseases can co-exist, share common risk factors and can adversely impact on prognosis, this service framework includes consideration of:

Standards for specific conditions:

- Chronic Obstructive Pulmonary Disease (COPD)
- Oxygen Therapy in COPD
- Asthma in Adults
- Asthma in Children and Young People
- Community Acquired Pneumonia (CAP) in Adults
- Community Acquired Pneumonia (CAP) in Children and Young People
- Obstructive Sleep Apnoea / Hypopnoea Syndrome (OSAHS) in Adults
- Obstructive Sleep Apnoea Syndrome (OSAS) in Children and Young People
- Long Term Ventilation in Adults
- Long Term Ventilation in Children and Young People
- Cystic Fibrosis
- Bronchiectasis
- Interstitial Lung Disease (ILD)

Standards relating to all conditions:

- Pulmonary Rehabilitation
- Transitional Care for Adolescents with Chronic Respiratory Disease
- Acute Oxygen Therapy
- Social and Emotional Support
- Information
- Training
- Medicines Management
- Palliative Care

Process for reviewing the Service Framework for Respiratory Health and Wellbeing

The development of Service Frameworks is overseen by a multidisciplinary programme board, which is chaired by the Chief Medical Officer.

Service Frameworks have a 3-year life cycle. At the end of this cycle, RQIA appraise the implementation of the Framework and report on its effectiveness. This appraisal informs a fundamental review, which not only evaluates the final achieved position against performance indicators and targets set, but also the effectiveness of the standards in the Framework and their continued utility and relevance.

The RQIA completed its Independent Review of the Implementation of the Respiratory Service Framework in March 2014. Their review report can be found here - http://www.rqia.org.uk/cms_resources/Independent%20Review%20of%20the%20Implementation%20of%20the%20Respiratory%20Service%20Framework.pdf

The fundamental review of this Framework has been lead by the Regional Respiratory Forum, supported by the Long Term Conditions Service Team, with further support provided by the wider group of relevant stakeholders. In order to take the review forward a project team was developed to lead the review of standards and performance indicators.

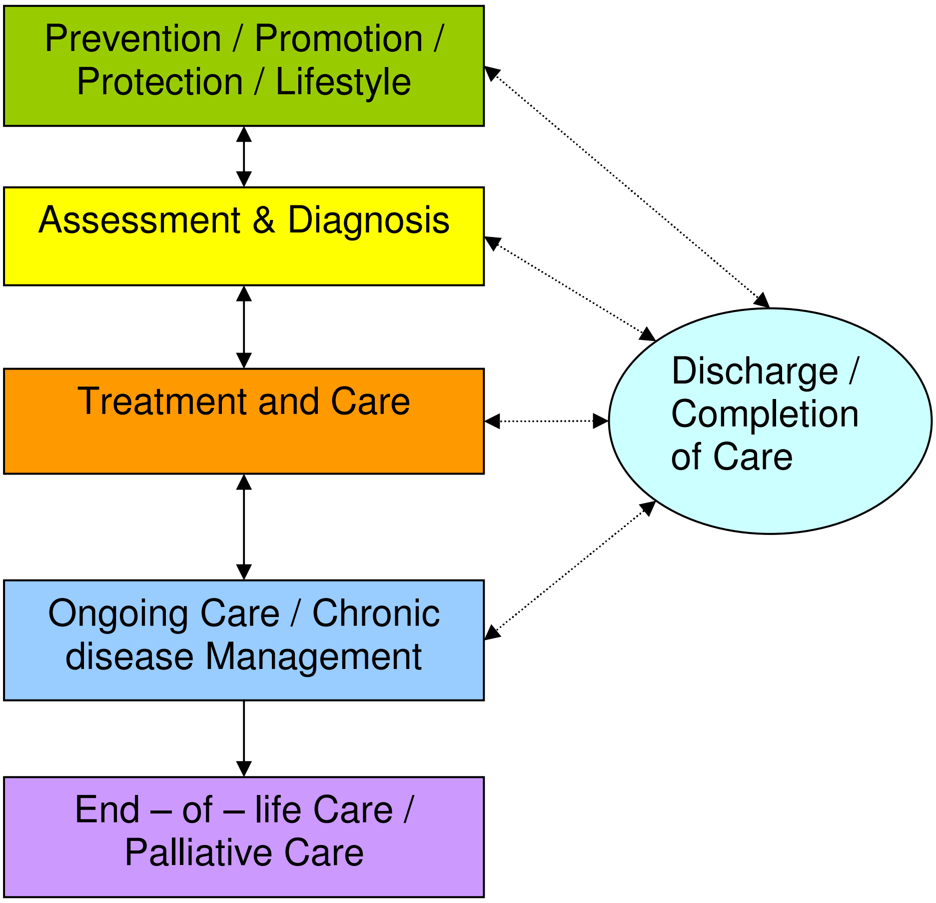
How to read the rest of this document

Each service framework follows an individual's journey, from prevention through to end-of-life care, taking into account the different health and social care needs of children and young people and adults.

Each standard sets out the evidence base and rationale for the development of the standard, the impact of the standard on quality improvement as well as the performance indicators that will be used to measure that the standard has been achieved within a specific timeframe. The standards are colour coded for ease of reference e.g. standards related to assessment and diagnosis will be yellow.

In addition, service frameworks include generic standards relating to safeguarding, involvement, communication, health improvement, safeguarding, independent advocacy, and carers. This Service Framework also includes standards relating to medicines management, training, information and social and emotional support.

Flowchart 1 – Template for development of service frameworks



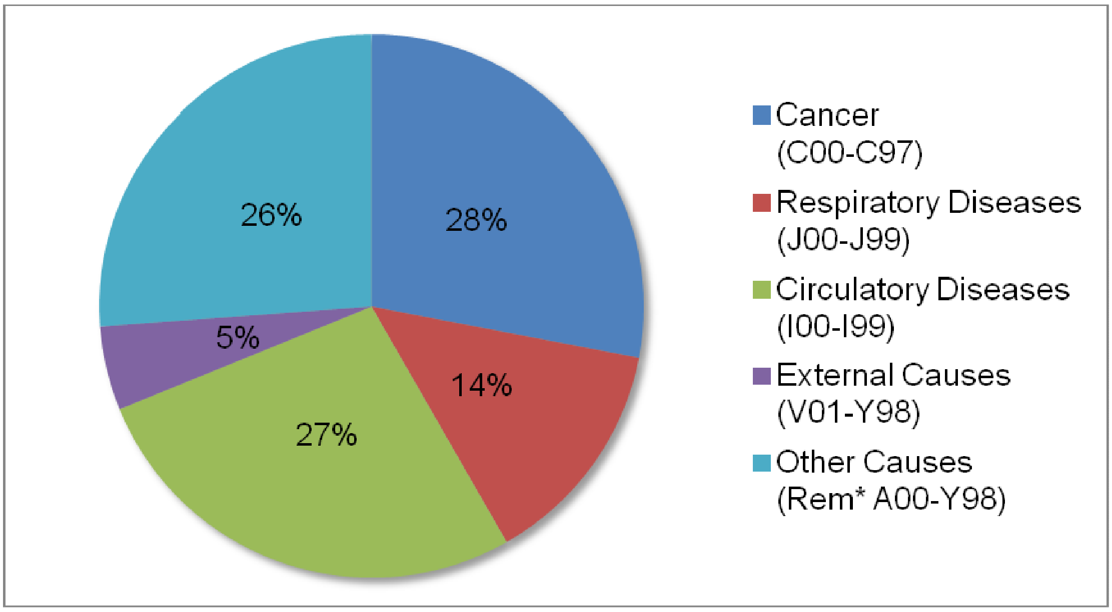
The rest of this document is divided into the following sections:

- **Section 3** explains why there is a need to develop a service framework for respiratory health and wellbeing and describes some of the key risk factors influencing the development of respiratory disease;
- **Section 4** sets out standards in relation to communication and personal and public involvement which will be relevant to a number of service frameworks under development;
- **Section 5** sets out standards in relation to health promotion and prevention which will be relevant to a number of service frameworks under development;
- **Section 6** sets out standards in relation to specific conditions associated with respiratory disease such as COPD, asthma, pneumonia etc; and,
- **Section 7** sets out standards for people who require supportive, palliative or end of life care which will be relevant to a number of service frameworks under development.

SECTION 3 - WHY DO WE NEED A SERVICE FRAMEWORK FOR RESPIRATORY WELLBEING?

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, on-going care and rehabilitation. The Respiratory Service Framework was one of the first to be developed, in reflection of the fact that respiratory disease is one of the biggest causes of death and disability in Northern Ireland[3]. Figure 1 illustrates that respiratory disease is the third most common cause of death in NI, after cancer and cardiovascular disease. The first edition of the Respiratory Service Framework was published in 2010. Every three years, the service framework will be updated to ensure it reflects the most recent evidence and guidelines.

Figure 1. Percentage of Deaths by Cause – Northern Ireland 2011



Source: NISRA

Death rates from respiratory disease in the UK and Ireland rank among the worst in Europe[4] , as illustrated in Figure 2. Using the World Health Organisation International Classification of Disease (ICD10) system, there were 2,023 deaths from respiratory diseases in Northern Ireland in

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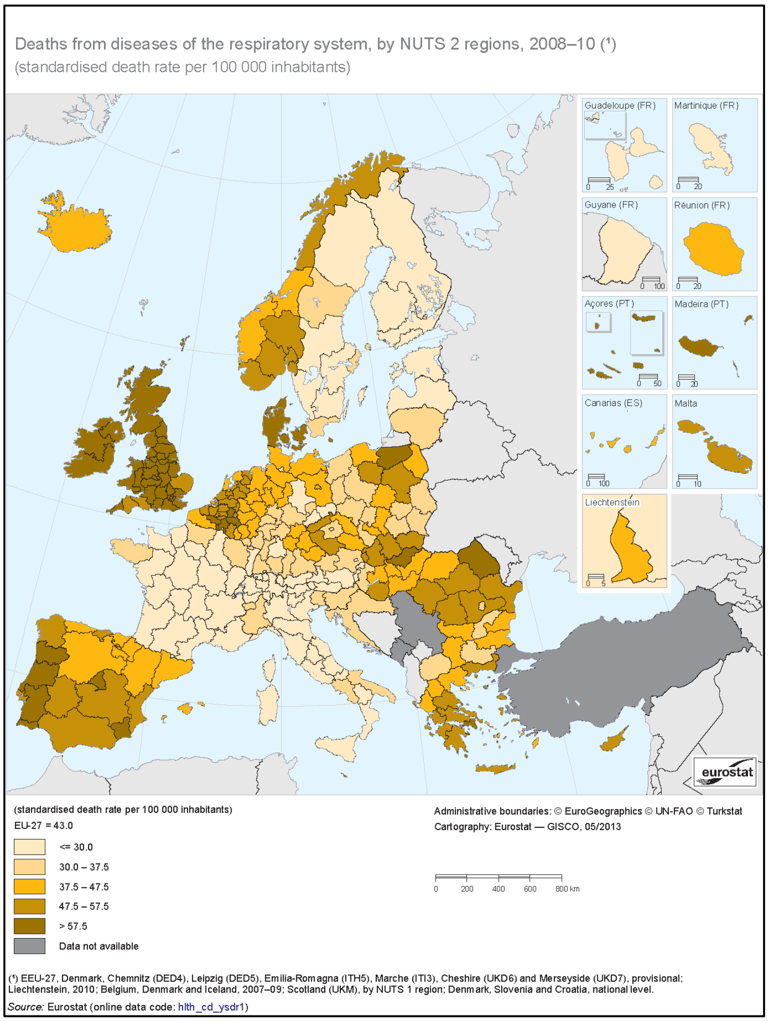
[3] NISRA Provisional Mortality Data 2012
[4] Eurostat

2012, accounting for 14% of the total deaths that year. 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 disease affecting the interstitium. It does not include tuberculosis, pulmonary hypertension, sleep apnoea, lung cancer and congenital diseases, which are classified elsewhere.

Figure 2. Standardised death rate for diseases of the respiratory system across Europe

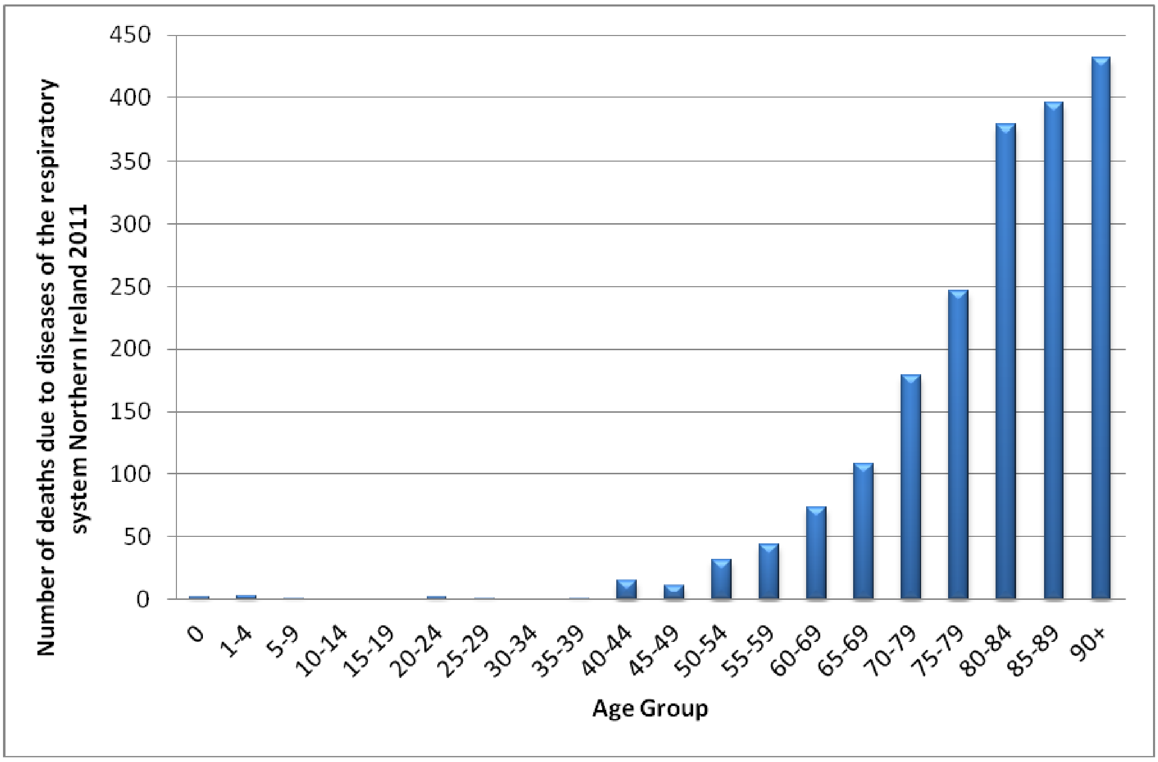


Source: Eurostat

Approximately 40% of deaths due to respiratory disease in 2012 were due to pneumonia, and a further 40% were from chronic lower respiratory diseases such as COPD. Asthma accounts for only a small proportion of deaths from respiratory disease, but may contribute significantly to potential years of life lost (PYLL), as the people affected are often younger. A table detailing numbers of deaths due to respiratory disease in Northern Ireland between 2001 and 2012, broken down by cause, can be found in appendix 1.

The majority of deaths from respiratory disease in Northern Ireland occur in the elderly population, as illustrated by figure 3. As people are now living longer and are more commonly 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, especially for those with chronic respiratory diseases.

Figure 3. Number of death due to diseases of the respiratory system by age group in Northern Ireland 2011

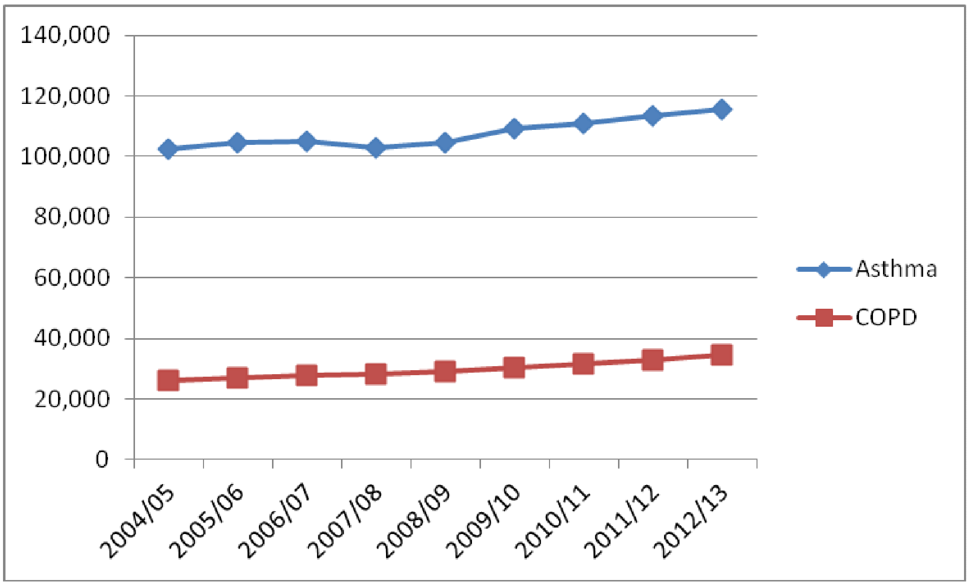


Source: NISRA

Morbidity

As for many conditions, it is very difficult to determine the true incidence and prevalence of respiratory disease in Northern Ireland. People with mild, self-limiting illnesses often manage their symptoms themselves, or seek advice from their local pharmacist. As a result, the episode will not be registered by primary or secondary health services. Others with chronic respiratory conditions such as COPD may remain undiagnosed as a result of attributing their symptoms to increasing age or ‘smokers cough'.[5] Prevalence registers maintained for GP practices can give an indication of the levels of respiratory disease in a population. The number of people recorded on GP registers in Northern Ireland with asthma and COPD has increased annually over the last decade as illustrated in figure 4. This is likely to be attributable in part to improved recording mechanisms and case finding strategies.

Figure 4. QOF Prevalence Registers for Asthma and COPD in Northern Ireland



Data source: DHSSPSNI

There were 33,958 hospital admissions with respiratory disease (ICD10 J0 – J99) as the primary diagnosis in Northern Ireland for 2012/13. The average length of stay was 6 days, and the total number of bed days for respiratory disease in this time period was 202,211. Over the last four years, the number of admissions and hospital days with bacterial pneumonia (ICD 10 codes J13 – J18) as the primary diagnosis has increased, as illustrated in figure 5. For COPD, the number of admissions has increased, but the number of hospital days has remained stable, suggesting a decrease in length of admission. Asthma admissions and hospital days have remained stable over this period.

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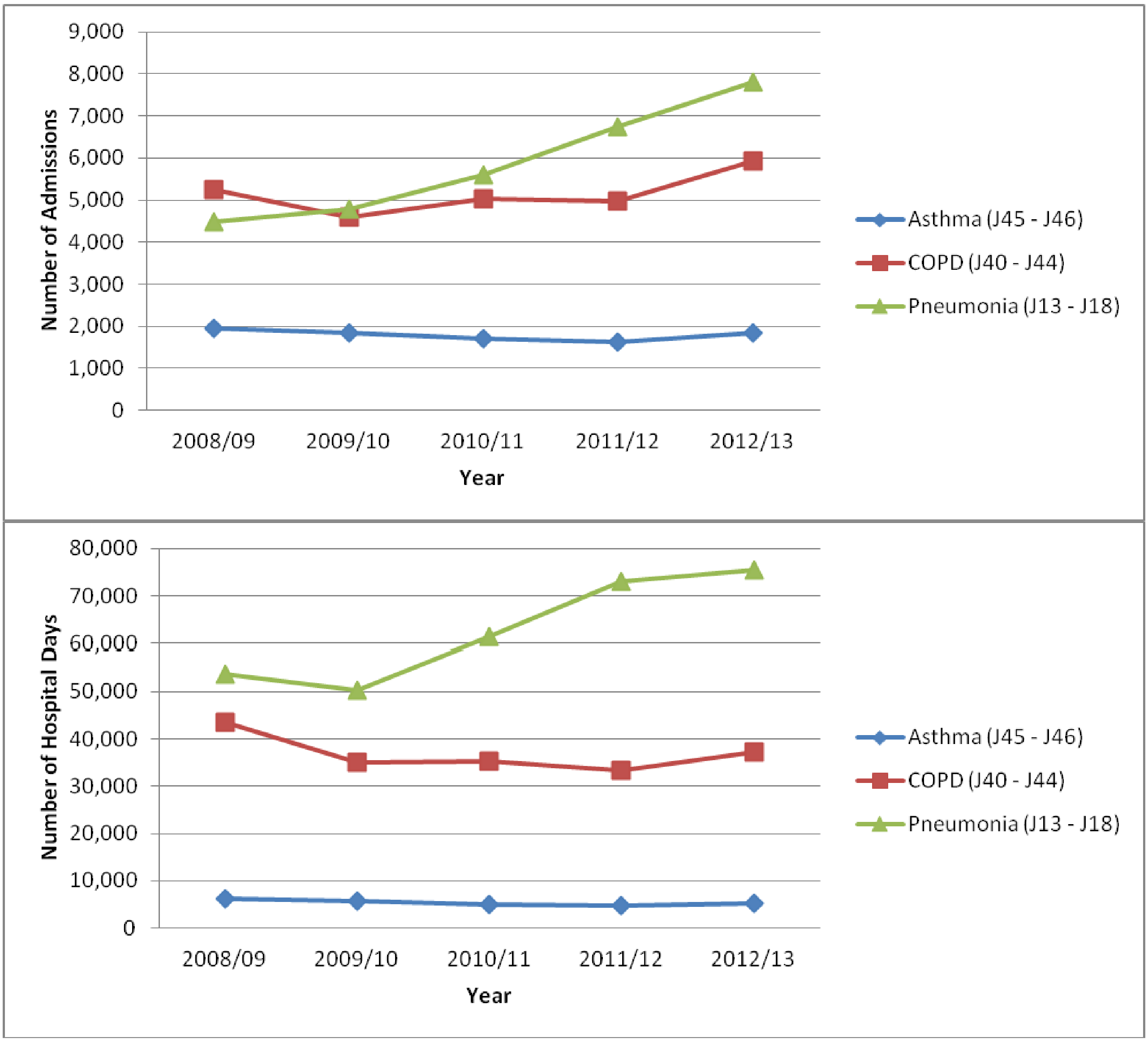
[5] Bednarek, M., Maciejewski, J., Wozniak, M., Kuca, P., & Zielinski, J. (2008). Prevalence, severity and underdiagnosis of COPD in the primary care setting. *Thorax*, *63*(5), 402-407.

Figure 5. Number of admissions and hospital days by primary diagnosis 2008/9 to 2012/3 in Northern Ireland



Data Source: PASDSS/BOXi/Admissions and Discharges Universe

Social Inequalities

Respiratory diseases occur in all sectors of the population, but those from the most deprived areas are disproportionately affected. Social inequality causes a higher proportion of deaths in respiratory disease than any other disease area, including cardiovascular disease, and it is estimated that 44% of all deaths from respiratory disease in the UK are associated with social class inequalities[6]. Although the death rate from respiratory disease in Northern Ireland has fallen over the last decade,

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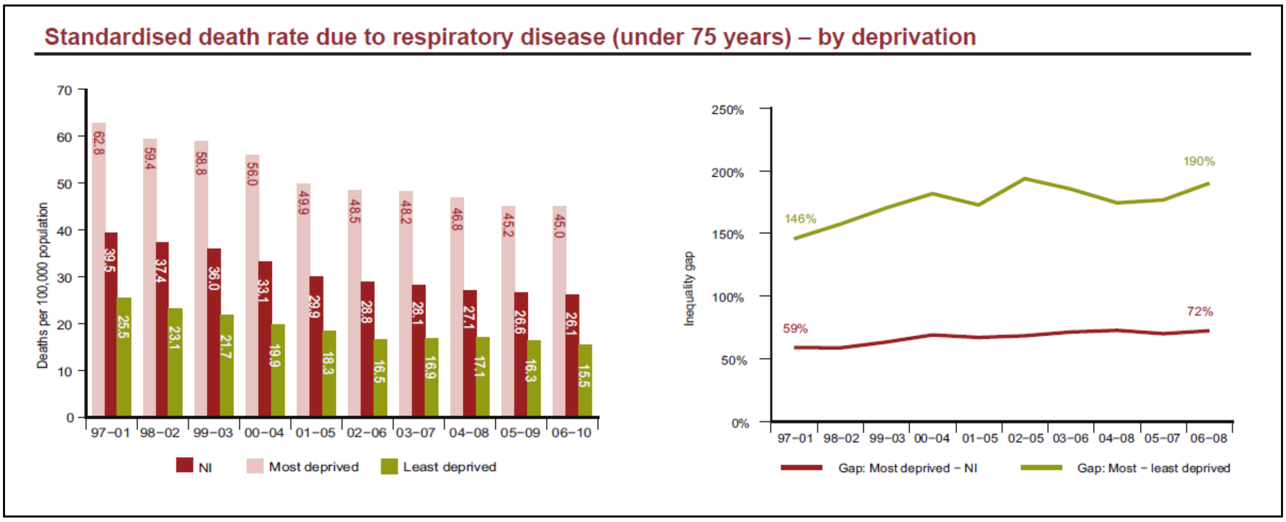
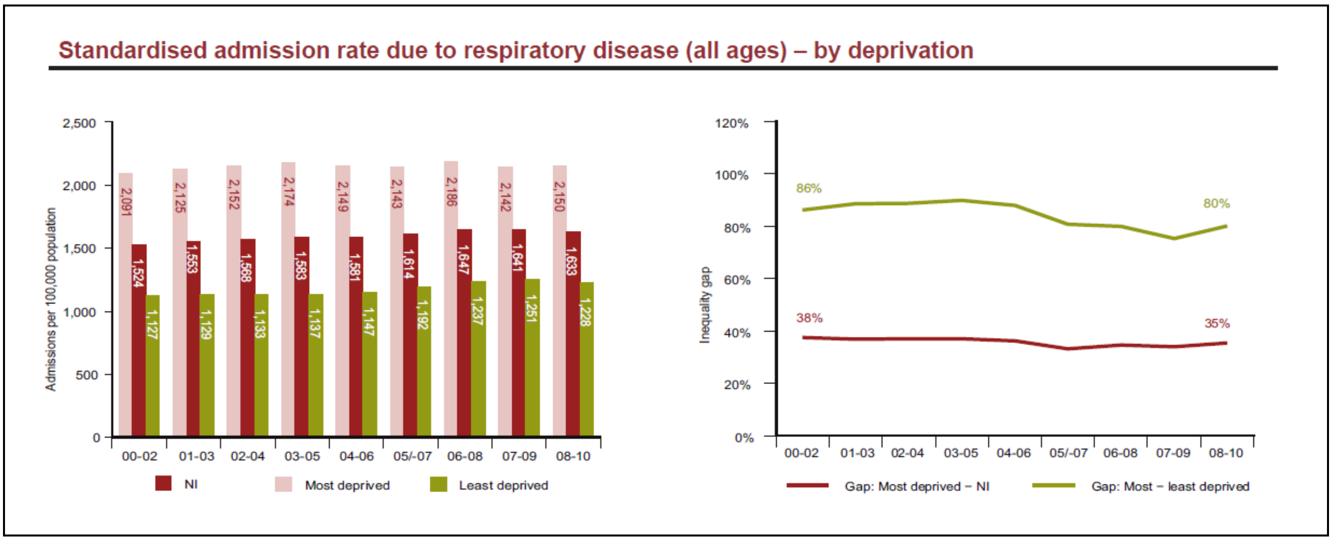
[6] BTS Report: **Burden of Lung Disease 2006**

the figure remains highest in the most deprived areas[7]. Between 2006 and 2010, the standardised death rate from respiratory disease in under 75 year olds was 3 times higher in the most deprived areas compared to the least (45.0 deaths per 10,000 compared to 15.5 deaths per 10,000 population respectively). The standardised admission rate due to respiratory disease was also considerably higher. One of the aims of this framework is to promote equity of care for people with respiratory disease, regardless of where they come from.

Figure 4. Standardised respiratory death and admission rates for the most and least deprived areas in Northern Ireland 1997 – 2010


Standardised death rate due to respiratory disease (under 75 years) – by deprivation


Standardised admission rate due to respiratory disease (all ages) – by deprivation

Source: DHSSPSNI

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[7] NI Health & Social Care Inequalities Monitoring System. Fourth Update Bulletin, June 2012. (DHSSPSNI).

Impact of Respiratory Disease on Health and Social Care Services

Care for people with respiratory diseases is a major contributor to the overall work and expenditure of health and social services. A report on the burden of respiratory disease by the British Thoracic Society reported that respiratory disease cost the United Kingdom (UK) £6.6 billion in 2004 – £3.0 billion in NHS care costs, £1.9 billion in mortality costs and £1.7 billion in morbidity costs[8]. Respiratory prescriptions account for 7% of all prescriptions in the UK.

There is considerable resource use attributable to respiratory disease in both the primary and secondary care sectors. In primary care, rates of patient consultations are higher for respiratory conditions than for any other type of illness, with the highest rates in infants and the elderly[9]. The most common cause for presentation is acute respiratory infection, followed by chronic respiratory disease such as COPD and asthma.

Respiratory conditions also account for a significant proportion of the secondary care workload. In 2012/3 in Northern Ireland there were 33,958 hospital admissions with respiratory disease as a primary diagnosis, accounting for 202,211 hospital bed days[10]. The most common primary diagnoses for respiratory admissions were infections of the respiratory tract and COPD. The average length of stay for respiratory admissions in 2012/3 was 6 days, with the longest admissions being for suppurative and necrotic pathologies. More detailed analysis of respiratory hospital admissions and bed days in Northern Ireland by primary diagnosis can be found in appendices 3 and 4.

Socioeconomic Consequences for the Community

Respiratory diseases may also have significant costs for the person affected and those caring for them. This may be a result of symptoms, as well as their treatment regime and the associated disruption to daily activities. Children and young people with undiagnosed or poorly controlled respiratory conditions may miss a significant number of days at school, limiting their social and academic potential. Adults with respiratory illness may be unable to participate in employment or leisure/social activities as a result of their condition and can be at risk of becoming socially isolated.

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[8] BTS Report: **Burden of Lung Disease 2006**

[9] Royal College of General Practitioners

[10] PASDSS/BOXi/Admissions and Discharges Universe

In the United Kingdom in 2011 approximately 5.3 million days of work were reported lost due to respiratory illness.[11] Respiratory conditions are the third largest contributor to total days of certified incapacity, with only mental/behaviour and musculoskeletal conditions contributing more days[12]. This emphasises the importance of psychosocial support for people with respiratory conditions.

WHAT CAUSES RESPIRATORY DISEASE?

The World Health Organisation (WHO) has identified a number of factors which increase the risk of chronic respiratory disease. Many of the risk factors associated with respiratory disease can be avoided or reduced. The major modifiable risk factor for chronic respiratory disease in developed countries is smoking, although other environmental exposures (both indoors and outdoors) can contribute. Nutrition and physical activity also have a role. There are also non-modifiable risk factors, such as ethnicity, genetic make-up and increasing age. Although these factors cannot be changed, an understanding of their impact can help to identify people who are at increased risk.

MODIFIABLE RISK FACTORS

Tobacco

Cigarette smoking is the major cause of preventable ill health and premature death in Northern Ireland, accounting for approximately 2,300 deaths every year[13]. Current evidence suggests that approximately one quarter of the population of Northern Ireland smoke, equating to just over 360,000 people[14]. Although this is a reduction from the figures seen in the 1990s, levels have remained relatively stable over the last few years, as illustrated in figure 5. Smoking is more prevalent in males than females, with levels of 27% and 23% respectively, and levels are highest in the 25-34 age group, at 33%.

Cigarette smoking is the most important risk factor for developing COPD in developed countries, and smoking cessation has been shown to be the most effective strategy to reduce the risk of COPD and to improve

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[11] Source: ONS, Labour Force Survey datasets

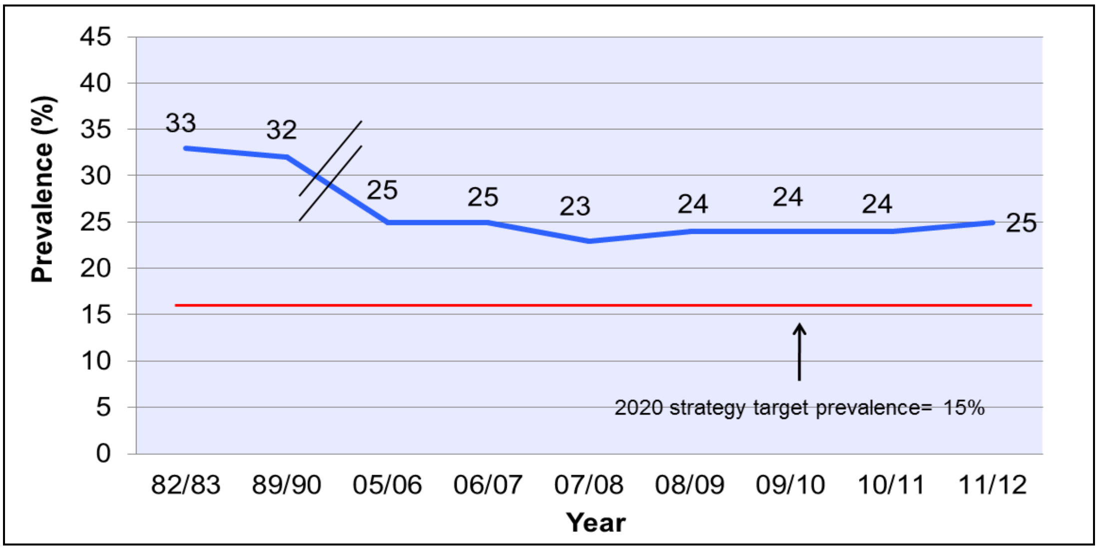
[12] BTS Report: **Burden of Lung Disease 2006**

[13] http://connect.publichealthagency.org/resources/health-and-social-wellbeing-improvement/smoking-cessation

[14] Health and Wellbeing Improvement Action Plan for Tobacco Control 2013/2014

outcomes of people at all stages of COPD[15]. Smoking also predisposes to a plethora of other illnesses, including lung cancer, lower respiratory tract infection, ischaemic heart disease and cerebrovascular disease. It is a risk factor for six out of eight of the leading causes of worldwide death[16].

Figure 5: Smoking prevalence in Northern Ireland 1982/83-2011/12



Source: Health Survey Northern Ireland DHSSPSNI, 2011-12.

Environmental Tobacco Smoke (ETS)

There is strong evidence for the adverse effects of exposure to environmental tobacco smoke (second hand smoke). The disease associations are similar to those for reported for smokers and include chronic respiratory diseases, cancer and heart disease. Since April 2007 in Northern Ireland it has been illegal to smoke in enclosed workspaces and public areas to try to protect people from the effects of ETS.

Children are also at risk from ETS exposure, particularly in the home environment. Parental smoking is associated with an increased risk of upper and lower respiratory tract infections, as well as an increased rate of sudden infant death syndrome.[17] There are also additional risks associated with maternal smoking during pregnancy, including a 40%

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[15] Van der Meer, R. M., et al. Smoking cessation for chronic obstructive pulmonary disease. Cochrane Database Syst Rev 1 (2001).

[16] Health and Wellbeing Improvement Action Plan for Tobacco Control 2013/2014

[17] Priest, Naomi, et al. Family and carer smoking control programmes for reducing children's exposure to environmental tobacco smoke. Cochrane Database Syst Rev 4 (2008).

increased risk of infant mortality, reduced birth weight and other complications of pregnancy[18].

Other Environmental Exposures

Exposure to pollutants, both indoors and outdoors, can contribute to the development of respiratory illness and exacerbate existing disease. Poor air quality is thought to result in more than 32,000 premature deaths in the UK each year alone. Long-term exposure to traffic-related air pollution has been linked to reduced life expectancy, and prolonged exposure to combustion-related fine particulate air pollution is an important environmental risk factor for cardiac, pulmonary and lung cancer mortality.[19] Exposure to allergens, such as dust mites, pollen, animal dander and fungal spores can also trigger symptoms in some people with asthma.

The workplace can also present risk factors for respiratory disease, including exposure to organic and inorganic matter. Asthma may be caused by the inhalation of organic agents, and is the fastest growing occupational disease in the UK. Pulmonary fibrosis and cancers can result from exposure to inorganic agents such as silica dust and asbestos. Workplace legislation is in place to reduce many of these occupational risks, but due to the long lag time between exposure and development of associated respiratory conditions, people are still presenting with disease linked to past exposure such as mesothelioma associated with asbestos.

Diet and Nutrition

Dietary factors can have both positive and negative influences on respiratory disease. The evidence for associations with specific foods is inconsistent, but it is widely accepted that good nutrition contributes to fighting infection. Overweight and obesity are associated with sleep apnoea syndrome, as well as a wide range of diseases affecting other body systems including diabetes, certain malignancies, ischaemic heart disease and joint problems.

Physical Activity

There is substantial evidence for the beneficial impact of regular physical activity on a wide range of health outcomes. With regard to the respiratory system, exercise can help to increase aerobic capacity and prevent muscular atrophy, as well as improve mood and general wellbeing. Research relating to the role of physical activity and

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[18] Health and Wellbeing Improvement Action Plan for Tobacco Control 2013/2014

[19] WHO Risk Factors for Respiratory Disease Report

respiratory disease has mainly focused on exercise as part of a pulmonary rehabilitations programme for people with COPD (secondary prevention). These have been shown to be a cost effective way to improve quality of life and outcomes in participants. People with other respiratory conditions such bronchiectasis may also benefit from such programmes.

WHAT DISEASES ARE COVERED BY THE RESPIRATORY SERVICE FRAMEWORK?

Chronic Obstructive Pulmonary Disease (COPD)

COPD is an umbrella term for people with chronic bronchitis, emphysema, or both. In people with COPD the airways are narrowed, causing obstruction of air flow to the lungs. In 2013, 1.8% of people registered with a GP in Northern Ireland were listed as having COPD[20]. It is likely that the true population prevalence is higher than this as it has been shown that COPD is under-diagnosed, especially in the early stages of disease[21]. Over the last decade, the number of people on COPD registers in Northern Ireland has risen, from just over 26,000 in 2004/5 to around 34,500 in 2012/3. This is likely to be partly attributable to improved register recording, but may also reflect earlier diagnosis and improved survival. COPD predominantly affects those over 35, and local study reported a prevalence of 6.3% among 40 – 69 year olds in Greater Belfast[22]. COPD is more prevalent in men than women, although the prevalence among woman is increasing.

Asthma in Adults and Children/Young people

Asthma is a relatively common respiratory condition which affects both adults and children. It is characterised by paroxysmal, reversible episodes of breathlessness and wheezing, which vary in severity and frequency from person to person.[23] In an acute asthma attack, there is narrowing of the airway, due to bronchospasm and activation of inflammatory pathways. This leads to symptoms such cough, wheeze, shortness of breath and chest tightness. In severe cases, asthma attacks can be life threatening and rapid treatment is essential.

Asthma contributes significantly to the workload of general practice, outpatient clinics and inpatient admissions[24]. In 2011/2 there were 113,518 people on GP asthma registers in Northern Ireland, including 21,325 individuals under the age of 15.[25] This gives an overall estimated population prevalence of 6%. Over the same time period there were

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[20] DHSSPSNI – Raw Disease Prevalence Data for Northern Ireland - as at 31 March 2013

[21] Soriano, Joan B., Jan Zielinski, and David Price. "Screening for and early detection of chronic obstructive pulmonary disease." The Lancet 374, no. 9691 (2009): 721-732.

[22] Murtagh, E., Heaney, L., Gingles, J., Shepherd, R., Kee, F., Patterson, C., & MacMahon, J. (2005). The prevalence of obstructive lung disease in a general population sample: The NICECOPD study. European journal of epidemiology, 20(5), 443-453.

[23] http://www.who.int/topics/asthma/en/

[24] BTS/SIGN Asthma Guidelines 2012

[25] QOF data 2011/12 (DHSSSPNI)

1,619 hospital admissions with asthma as a primary diagnosis, accounting for 4,676 bed days[26].

Community Acquired Pneumonia in Adults and Children/Young People

Community acquired pneumonia (CAP) refers to a lower respiratory tract infection contracted in the community setting. The incidence of CAP varies markedly with age, occurring most frequently in the elderly and very young. The overall incidence has been estimated at between 5–11 per 1000 population per year in adults, with incidence rates of over 30 per 1000 population reported in children under 5 and elderly people[27].

It is one of the major causes of morbidity and mortality from respiratory disease in Northern Ireland, accounting for approximately 40% of deaths from respiratory disease in 2012. There were 7,798 admissions with CAP in 2012/13, accounting for 75,466 bed days.[28]

Obstructive Sleep Apnoea/Hypopnoea Syndrome

Obstructive sleep apnoea / hypopnoea syndrome (OSAHS) is a condition in which the upper airway collapses and briefly obstructs breathing, disrupting sleep.[29] One of the major risk factors is obesity. OSAHS can result in excessive daytime sleepiness, which is a major risk factor for serious road traffic accidents. Untreated OSAHS is also a risk factor for the development of hypertension and cardiovascular disease.

OSAHS is thought to be considerably underdiagnosed, partly due to lack of awareness of the condition among the public and healthcare professionals. Studies conducted around 10-15 years ago suggest that the condition affects 2–4% of middle aged males and about 1-2% of females, but the true prevalence is likely to be higher, especially as levels of obesity have risen. Recent estimates suggest that only 20–30% of affected individuals have currently been diagnosed in the UK. In a

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[26] PASDSS/BOXi/Admissions and Discharges Universe

[27] BTS Community Acquired Pneumonia Guidelines for adults (2009) and children (2011)

[28] PASDSS/BOXi/Admissions and Discharges Universe

[29] BTS Service Specification for Investigation and treatment of Obstructive Sleep Apnoea Syndrome 2009

study of more than 3000 randomly selected males in Northern Ireland in 2001, almost 20% reported excessive daytime sleepiness.[30]

Obstructive Sleep Apnoea Syndrome (OSAS) in Children and Young People

Obstructive Sleep Apnoea Syndrome (OSAS) is a disorder in children characterised by repetitive episodes of upper airway obstruction, intermittent hypoxaemia and hypercapnoea, and snoring. Most children snore at some time but not all have OSA. The causes differ from those in adults and include the following:

- Upper airways physical narrowing:
  - adenotonsillar hypertrophy
  - craniofacial structural abnormalities.
- Abnormalities of upper airway tone:
  - Down's Syndrome.
- Obesity:
  - Common obesity – this is increasing in children in Northern Ireland and is likely to be associated with an increase in OSA cases.
  - Syndromes associated with morbid obesity e.g. Prader Willi syndrome, post craniophyrangioma

Limited epidemiological data suggest that the disorder affects up to 3% of 'middle-aged' children and may be higher in those 3-6 years of age (13%). Childhood OSA is thus relatively common and may cause significant morbidity, including cardiovascular disease, behavioural problems and impaired academic ability[31].

Long term ventilation

Long term ventilation (LTV) refers to the provision of invasive or non-invasive respiratory support to individuals with chronic respiratory failure. The main groups of people requiring access to LTV are those with:

i. Respiratory conditions e.g. sleep apnoea

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[30] Nugent, A. M. , Gleadhill, I. , Mccrum, E. , Patterson, C. C. , Evans, A. and Macmahon, J. (2001), Sleep complaints and risk factors for excessive daytime sleepiness in adult males in Northern Ireland. Journal of Sleep Research, 10: 69–74.

[31] Montgomery-Downs, H. E., V. M. Crabtree, and D. Gozal. Cognition, sleep and respiration in at-risk children treated for obstructive sleep apnoea. European Respiratory Journal 25, no. 2 (2005): 336-342.

ii. Neuromuscular diseases e.g. motor neurone disease and duchenne muscular dystrophy
iii. Spinal cord injury

At present there are approximately 300 people receiving LTV in Northern Ireland, including 50 children[32]. The majority of these have respiratory or neuromuscular conditions, with only a small number of people with spinal cord injuries. The prevalence of many of the conditions in which LTV is indicated is increasing, and it is expected that the demand will increase in reflection of this. The number of children with neuromuscular disease receiving LTV is also likely to increase as the benefits of this treatment are realised. In the last decade non-invasive ventilation (NIV) has considerably extended survival in children with these conditions and simultaneously improved quality of life[33].

Neuromuscular disorders can also impair a person's ability to cough effectively. This results in failure to clear secretions from the airway and predisposes to infections of the respiratory tract. Cough assist devices (using mechanical insufflation-exsufflation) have been shown to improve cough effectiveness and reduce respiratory tract infections and episodes of respiratory failure in people with neuromuscular conditions[34]. Based on local population prevalence estimates of neuromuscular conditions, it is estimated that there are 318 people in Northern Ireland who would benefit from these devices[35]. The same report estimated that approximately 160 people in Northern Ireland are likely to require NIV as a result of neurological or muscular disease.

Cystic Fibrosis

Cystic fibrosis (CF) is an autosomal recessive genetic disorder characterised by defective mucociliary clearance and chronic airway infection.[36] The underlying genetic defect results in abnormal transport of chloride and sodium across an epithelium, leading to thick, viscous secretions which primarily affect the lungs and digestive system. CF is the most common life threatening inherited condition in the UK, and is

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[32] Complex Home Ventilation in Northern Ireland – unpublished needs assessment (2013)

[33] Simonds, Anita K. Recent advances in respiratory care for neuromuscular disease. CHEST Journal 130, no. 6 (2006): 1879-1886.

[34] Homnick, Douglas N. Mechanical insufflation-exsufflation for airway mucus clearance. *Respiratory care* 52.10 (2007): 1296-1307.

[35] Complex Home Ventilation in Northern Ireland – unpublished needs assessment (2013)

[36] Cystic fibrosis Prof Brian P O'Sullivan MD,Steven D Freedman MD The Lancet - 30 May 2009 (Vol. 373, Issue 9678, Pages 1891-1904)

particularly prevalent in Northern Ireland because of a high gene carriage rate (around 1/20 of the population). There are currently just under 500 people diagnosed with CF in Northern Ireland, all of whom attend the adult and paediatric CF centres in Belfast.[37]

CF was previously considered to be a condition of children, but the prognosis has improved over the last decades to the extent that there are now slightly more adults than children and young people with CF in Northern Ireland. Registry data showed the median survival for people with CF in 2012 was 43.8, though median age at death remains in the late 20s. Improved survival is accounted for by early diagnosis due to neonatal screening and centralised care with specialist multidisciplinary teams.

Bronchiectasis

Bronchiectasis is a condition in which there is permanent dilatation of the bronchi, predisposing to inflammation and infection[38]. This may result from a number of underlying conditions including pneumonia, cystic fibrosis, immunodeficiency and primary ciliary dyskinesia. Other systemic conditions such as rheumatoid arthritis and inflammatory bowel disease are also associated with bronchiectasis. High resolution CT scanning is required to make an accurate diagnosis.

The exact prevalence is unclear and likely to be an underestimate of the true prevalence, but it is known that incidence increases with age, although children can also be affected. There are likely to be around 5,000 people in Northern Ireland with bronchiectasis resulting in around 500 hospital admissions annually[39].

Interstitial Lung Disease

Interstitial lung diseases (ILD) encompass a large range of disorders (over 200), affecting the functional part of the lung or the ‘lung parenchyma.’ There is no universally agreed classification of the disorders, but they all present similarly with increasing shortness of breath and widespread shadowing on a chest x-ray. The most frequently occurring are idiopathic pulmonary fibrosis (IPF) and sarcoidosis. ILD also includes environmental lung diseases such as extrinsic allergic alveolitis and asbestosis.

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[37] Port CF Registry Data

[38] Barker, Alan F. Bronchiectasis. New England Journal of Medicine 346, no. 18 (2002): 1383-1393.

[39] PASDSS/BOXi/Admissions and Discharges Universe

i) **Idiopathic pulmonary fibrosis:** Pulmonary fibrosis is a scarring of the lung tissue, resulting in the lungs losing the ability to transfer oxygen into the bloodstream as effectively. The term idiopathic refers to the fact that the cause is unknown. Around 90 new cases of idiopathic pulmonary fibrosis (IPF) are expected each year in Northern Ireland. A UK-based study, using information from 255 GP practices from 1991 to 2003, estimated the crude incidence rate of IPF in Northern Ireland as 3.26 per 100,000 person-years, with more cases in women than in men[40]. The incidence of IPF in the UK as a whole increased with age (0.5 per 100,000 person-years in the under 55 age group, increasing to 25 per 100,000 person-years in the 75-84 year age group). During the period of the study the incidence increased in all age groups by 11% per annum - a phenomenon which could not be attributed to population ageing alone. The median survival of people with a diagnosis of IPF was 3.9 years.

ii) **Sarcoidosis:** Sarcoidosis is an immune system disorder characterised by non-caseating granulomas (inflammatory nodules). Again the cause is unknown. The expected number of new cases of sarcoidosis in Northern Ireland each year is approximately 200. From the study described above, the crude incidence rate of sarcoidosis in Northern Ireland was estimated as 7.71 per 100,000 person-years. The rates were similar in males and females, with the highest incidence in the 25-35 age group. The crude mortality rate was 14 per 1000 person years, which was about double that of a comparison cohort (matched general practice population).

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[40] J Gribbin, RB Hubbard, I Lejeune, CJP Smyth, J West, LJ Tata. Incidence and mortality of idiopathic pulmonary fibrosis and sarcoidosis in the UK. *Thorax* 2006; 61: 980-985

SECTION 4 - STANDARDS FOR COMMUNICATION AND INVOLVEMENT

Effective communication with service users is essential to all aspects of the adequate planning and provision of health and social care services. Without effective communication, there can be no effective participation by service users in any partnership with Health and Social Care.

Communication will be of increasing importance as HSC strategies and targets are worked through. For example, it is essential to develop patient partnerships to achieve success in disease prevention and in the management of long-term conditions. It will be essential to involve service users in strategic change such as an increase in home and community-based service provision and reduced dependence on hospitals if such initiatives are to proceed at all.

Poor communication tends to be at the heart of most complaints, much negative experience and many negative perceptions and attitudes on the part of service users.

For many, good communication may be seen as to be assumed, or implicit. However, good communication cannot be presumed. It is a function requiring specific skill and training, dedicated resources, priority and focus to the same extent that clinical service provision, service planning and governance require these things.

For these reasons, a specific standard for communication should be part of all service frameworks. Making good communication part of the guiding ethos of the framework is unlikely to ensure that it is addressed with the same focus and priority as any of the individual targets.

It might be suggested that most of those charged with delivering on the frameworks will focus first on what it specifically requires them to do within their area of responsibility. A standard on communication requires action at the same level and in the same way.

Personal and Public Involvement

Personal and Public Involvement means discussing with those who use our services and the public: their ideas, your plans; their experiences, your experiences; why services need to change; what people want from services; how to make the best use of resources; and how to improve the quality and safety of services

Personal and Public Involvement (PPI) is a central component of the quality agenda, which aims to improve health and social care service provision in Northern Ireland and the individual experiences of those who use these services.

As a key Departmental policy it is integral to the delivery of high quality services. It is one of the key strands underpinning the Department's 10-year Quality Strategy, *Quality 2020,* which was published in November 2011. It is also seen as one of the key features of effective clinical and social care governance, and is one of the central tenets running through the five key themes of the *Quality Standards for Health and Social Care*. Our success in protecting and improving quality of services as safe, effective and patient/client focused will be the greater with effective involvement.

Overarching standard 1: Communication (Generic)
All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.

Rationale:
Effective communication has a significant impact on all aspects of care provision from disease prevention, to diagnosis, to self-management of long-term conditions. Poor communication is a significant factor in most complaints against HSC organisations.

Evidence:
Guidance on strengthening Personal and Public Involvement in Health and Social Care (DHSSPS, 2007) http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

Good Medical Practice (GMC, 2013)
http://www.gmc-uk.org/guidance/good_medical_practice.asp

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

Quality Dimension

Safe
Good communication with patients/clients/carers enables adequate understanding of, consent to and compliance with treatment and care and contributes to audit and monitoring.

Accessible
Good communication helps to deliver and sustain appropriate patient/client/carer access to services and a clear understanding of the role and responsibilities of the service user in achieving health and care outcomes.

Effective
Health and care outcomes themselves are enhanced through improved patient partnership and dialogue, including, but not limited to - diagnosis, self-referral, health promotion, disease prevention and management of long term conditions.

Efficient
Good communication will lead to easily understandable information and messages reaching service users and carers and will limit potential for delays in treatment or care due to poor communication.

Equitable
As a universal requirement, good communication helps to ensure input by all service users on all aspects of the services they receive assisting in the highlighting of gaps in provision and areas for improvement.

Person Centred
Patient centredness cannot be delivered or claimed in the absence of good communication with service users and carers. Good communication is a prerequisite of patient centredness.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of patients and clients expressing satisfaction with communication	Patient and Client Experience monitoring report Annual Accountability Report	Establish baseline and set target Report percentage increase of patient and client satisfaction with communication Report percentage increase of patient and client satisfaction with communication	March 2014 March 2015 March 2016

Overarching Standard 2 – Involvement (Generic)
All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.

Rationale:
Actively involving patients and the public in the planning and provision of health care in general has been noted to bring many advantages to both those who receive and those who provide care. These include:

- Increased patient satisfaction and reduction in anxiety with positive health effects
- Improved communication between service users and professional staff
- Better outcomes of care with greater accessibility and acceptability of services
- Bridging of the gap between those who avail of services and those who provide care
- Recognition of the expertise of the recipient of care developed through experience

Evidence:
Policy Circular Guidance for HSC organisations on arrangements for implementing effective personal and public involvement in the HSC (DHSSPS, 2012)
http://www.dhsspsni.gov.uk/arrangements_for_implementing_effective_personal_and_public_involvement_in_the_hsc.pdf

Guidance on strengthening Personal and Public Involvement in Health and Social Care (DHSSPS, 2007) http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

A Healthier Future 2005-2025 (DHSSPS)
http://www.dhsspsni.gov.uk/show_publications?txtid=7282

Healthy Democracy (NHS National Centre for Involvement, 2006)
http://www.nhscentreforinvolvement.nhs.uk/index.cfm?content=90

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

Quality Dimensions

Safe
Personal and Public Involvement enhances governance at all levels through the routine inclusion of patient and carer input, experience and the issues arising from this in the planning, delivery and monitoring of services.

Accessible
Personal and Public Involvement ensures that the level and means of engagement with service users, carers and the public are appropriate to the needs of the service and of service users and carers.

Effective
The development of partnerships with service users, carers and the public contributes to positive health and social care outcomes generally. It is a prerequisite of success where patient and public participation is the decisive factor in achieving the outcome – for example, in health promotion and disease prevention.

Efficient
Embedding Personal and Public Involvement at all levels of organisational decision making and delivery provides the opportunity to listen to those who use our services. By taking into account the needs of patients, clients, carers and the general public, Health and Social Care organisations ensure that resources are directed efficiently and most appropriately.

Equitable
Well developed and widespread Personal and Public Involvement contributes to equitable services through the active engagement of service users, carers and the public in planning, priority setting and decision-making.

Person Centred
Personal and Public Involvement is a necessity for the successful development of patient centred services

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of job descriptions containing PPI as responsibility Year 1: senior and middle management Year 2: designated PPI leads at all levels of HSC organisations Year 3: all new job descriptions	Audit sample of job descriptions	Establish baseline and set target	March 2014
		Monitor progress	March 2015
		100% - in all new job descriptions.	March 2016
Percentage of Patients and Clients expressing satisfaction	Patient and Client Experience monitoring report	Establish baseline and set target	March 2014
		Report percentage increase of Patient and Client satisfaction	March 2015
	Annual Accountability Report	Report percentage increase of Patient and Client satisfaction	March 2016
Percentage of staff who have gained PPI training (details to be agreed for 2014/15)	Annual Accountability Report	Conduct training needs assessment for PPI.	March 2014
	Training Report	Commission design of PPI training programme	March 2015
		Establish baseline and set target Monitor percentage of staff trained at different levels in PPI	March 2016

Overarching standard 3: Independent Advocacy (Generic)
Users of health and social care services and their carers should have access to independent advocacy as required.

Rationale:
People engage with health and social care services at times in their lives when they might be vulnerable or in need of support and / or guidance in relation to decisions about their health and wellbeing.

For a whole raft of reasons (age, disability, mental health issues, gender, ethnic origin, sexual orientation, social exclusion, reputation, abuse and family breakdown and living away from home or in institutions), they may also feel discriminated against or simply excluded from major decisions affecting their health and wellbeing. It is at such times that independent advocacy can make a real difference because it gives people a voice; helps them access information so that they can make informed decisions and participate in their own care or treatment.

Independent advocacy is also a means of securing and protecting a person’s human rights; representing their interests; and ensuring that decisions are taken with due regard to a person’s preferences or perspectives where, for whatever reason, they are unable to speak up for themselves.

In strategic terms independent advocacy can contribute to increased social inclusion and justice; service improvements in health and wellbeing; reductions in inequalities across the health and social care sector; and enhanced safeguarding arrangements.

Independent advocacy can be delivered in a number of different ways and people may need different types of advocacy at different times in their lives. The most common models are self/group advocacy; peer advocacy; citizen advocacy; and individual/issue-based advocacy (also known as professional advocacy).

In this context, independence means structurally independent from statutory department or agency providing the service. The advocacy provider must be free from conflict of interest as possible as possible both in design and operation and must actively seek to reduce any conflicting interests.

Independent advocacy should be available throughout the care pathway and, in particular, should be available early in the process as this may prevent a crisis developing. An advocacy service should apply not just to service users but to their carers and families.

There is currently a proposal to introduce a statutory right to an independent advocate in the proposed Mental Capacity Bill. Guidance on this right will be issued once the Bill has been finalised.

To be effective users need to be aware of advocacy services. Therefore they need to be promoted through accurate and accessible information.

Relevant health and social care staff should be aware of the benefits of independent advocacy and the particular importance of independence from service provision.

Evidence:

Alzheimer's Society (2009) Listening Well. Available at http://www.alzheimers.org.uk

Department of Health, Social Services and Public Safety (2010) Advocacy Research Summary Paper. Available at http://www.dhsspsni.gov.uk/advocacy-research-summary-paper-of-advocacy-provision-october-2010.pdf

Policy for Developing Advocacy Services: A Guide for Commissioners (2012) Available at http://www.dhsspsni.gov.uk/developing-advocacy-services-a-guide-for-commissioners-may-2012.pdf

Horton, C (2009) Creating a Stronger Information, Advice and Advocacy System for Older People. London; Joseph Rowntree Foundation

Social Care Institute for Excellence (2009) At A Glance 12: Implications for Advocacy Workers available at http://www.scie.org.uk/publications/ataglance/ataglance12.asp

Seal, M. (2007) Patient Advocacy and Advance Care Planning in the Acute Hospital Setting – Australian Journal of Advanced Nursing
Vol 24, No 4, pp29-36

Wright, M. (2006) A Voice That Wasn't Speaking: Older People Using Advocacy and Shaping it's Development, Stoke-on-Trent, OPAAL UK (Older People's Advocacy Alliance)

Bamford Review (2006). Review of Mental Health and Learning Disability (NI), Human Rights and Equality of Opportunity Available at www.dhsspsni.gov.uk/bamford

Knox, C. (2010) Policy Advocacy in Northern Ireland. University of Ulster, Jordanstown

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
Local Commissioning Groups
Primary Care Partnerships
Health and Social Care Trusts
General Practitioners / Primary Care
Voluntary and Community Sector
Independent Sector
Patient Client Council

Quality Dimensions

Safe
Advocacy services can safeguard users from abuse and exploitation by ensuring that their rights are upheld and their voice heard

Effective
Advocacy can help prevent crises in a person's life which otherwise may result in an intervention that has greater resource implications. Advocacy can enhance capacity building at a community and individual level, which can ultimately reduce dependency on other health and social care services. An advocacy service can promote equality, social justice and inclusion of the most vulnerable and disadvantaged

Person Centred
Advocacy services can enable individuals to access information, express their views and wishes and make informed choices about their own health and well being. The service is geared to needs of the individual. The service user will receive a service that best meets their needs at a time, which evidence shows, to be effective and to have maximum impact.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
To be determined			

Overarching standard 4: Identifying & Supporting Carers (Generic)
All Health & Social Care staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.

Rationale:
Carers are central to providing health and social care. People want to live in their own homes as independently as possible and family caring is critical in achieving this goal. Breakdown in caring has a major impact on readmission rates to hospital and unnecessary admissions to residential and nursing home care placements.

Caring is both a demanding and rewarding activity. Evidence shows that unsupported caring can have a negative impact on the physical, social and emotional well being of an adult carer. It is in everyone’s interest to ensure that carers can continue to care for as long as they wish and are able to, without jeopardising their own health and wellbeing or financial security, or reducing their expectations of a reasonable quality of life.

Young carers (children and young people up to the age of 18 years who have a substantive caring role for a member of their family) often do not have an alternative but to be a carer. These children can be lonely, isolated, lose friendships and miss out on education and social activities. Young carers are frequently involved in activities that are developmentally inappropriate and the impact on their lives is unknown. Many young carers go unidentified. This highlights the need to identify young carers and provide support and assistance which will promote their health, development and inclusion in educational and social activities.

Early intervention, individually tailored to the needs of the carer and the cared for person, can be crucial in avoiding breakdown in the caring role. Forming meaningful partnerships with carers and making agreements with them about support to be provided is essential. Carers identify their requirements as respite care, information, personal care for the cared for person and practical and emotional support to continue in their role. This highlights the need for service planning and commissioning based on partnership working between statutory and independent sector and involvement of carers or their representatives to shape future services.

To enable carers to access the right information, support and services, current methods for identifying carers and encouraging them to acknowledge their caring role need to be enhanced. Under the Carers and Direct payments Act, all staff have a duty to inform carers. Staff should be particularly proactive in identifying the presence of younger and older carers.

One of the most important and far-reaching improvements in the lives of carers will be brought about by how health and social care staff view and treat them. Changes in staff knowledge of carers' issues could promote a more positive attitude to carers and this would make a significant difference to the lives of carers. Services should recognise carers both as individuals in their own right and as key partners in the provision of care and support.

Evidence:
Department of Health, Social Services and Public Safety (2006) Caring for Carers Recognising, Valuing and Supporting the Caring Role. Available at http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

Department of Health, Social Services and Public Safety / Department for Social Development (2009) Review of the Support Provision for Carers. Available at www.dhsspsni.gov.uk/review-of-support.

Department of Health, Social Services and Public Safety (2009). Circular HSS (ECCU) 2/2009, "Regional Carers Support and Needs Assessment Tool" Available at www.dhsspsni.gov.uk.

Department of Health, Social Services and Public Safety (2006). Circular HSS (ECCU) 4/2006, 'Identification of Carers'. Available at www.dhsspsni.gov.uk.

Department of Health, Social Services and Public Safety (2008). Circular HSS (ECCU) 3/2008, Good Practice Guidance – Training for Carers. Available at www.dhsspsni.gov.uk.

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Northern Ireland Statistics and Research Agency (2001) Northern Ireland Census of population. Available at www.nisra.gov.uk

Olsen R (1996) "Young Carers: challenging the facts and politics of research into children and caring". Disability and Society, 11 (1), 41-54

Patient & Client Council NI (2011) A report of the experiences and circumstances of 16 year old carers. Available at www.patientclientcouncil.hscni.net Social Policy Research Unit, University of York (2004) “Hearts and Minds -The Health Effects of Caring”, Michael Hirst. Available at www.york.ac.uk Southern Health and Social Care Trust (2011) General Practitioners Carers Support Project: Project Report. Available at www.southerntrust.hscni.net/services/carers Schubotz, D. and McMullan G. (2010) The Mental and Emotional Health of 16-Year Olds in Northern Ireland: Evidence from the Young Life and Times Survey. Belfast: Patient and Client Council Report. Tommis, Y. and Robinson, C.A. (2009) Carers *Interventions Assessed.* Wales Office of Research and Development.
Responsibility for delivery / implementation
Health and Social Care Board Public Health Agency Local Commissioning Groups Health and Social Care Trusts General Practitioners/ Primary Care / Pharmacy Independent Sector Department for Social Development and Department of Education
Quality Dimensions
Safe Carers will be encouraged to identify themselves as carers and to access information and support to protect and promote their own health and well-being and minimise the negative impact of caring **Effective** Involving carers in the planning, delivery and evaluation of services improves outcomes for the carer and cared for person. Carers will be identified and supported best through partnerships between the statutory and voluntary sector and by good referral processes. Carers will be identified and signposted to help and support as early as possible in their journey and at times of crisis/transition. **Person Centred** Carers will feel valued and able to access the support they need. Staff will be

facilitated to understand and value the role of carers. Carers will be recognised as real and equal partners in the delivery of care. All carers, irrespective of age, who they care for or where they live will be directed toward appropriate agencies that can offer advice and support.			
Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Number of front line staff in a range of settings participating in Carer Awareness Training Programmes	Trust Training Report (including Induction programmes)	20% 50%	March 2015 March 2016
The number of carers who are offered Carers Assessments	Health & Social Care Board/ DHSSPS Returns	Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually
The percentage of carers who participate in Carers Assessments	Health & Social Care Board/ DHSSPS returns	Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually

SECTION 5 – STANDARDS FOR HEALTH IMPROVEMENT / PROTECTION

Health is affected by a wide range of factors – individual factors such as age, gender and genetic make-up. These factors are modified by an individual's lifestyle. However, lifestyle is influenced by the environment in which individuals live. Social networks, working conditions, housing, employment, education, and health and social care services, all impact on our health and social wellbeing.

It is known that people in different circumstances experience avoidable differences in health, social wellbeing and length of life - inequalities in health arise because of inequalities in society. In Northern Ireland, males living in the 10% least deprived areas can expect on average to live almost 12 years longer than their counterparts living in the 10% most deprived areas and for females the gap is more than 8 years.

Health improvement involves partnership working across HSC and the other statutory, community and voluntary sectors to reduce health inequalities. This is achieved by improving people's life circumstances, promoting healthy lifestyles and providing services to support and empower individuals to improve their own health and social wellbeing.

Cardiovascular disease is one of the main causes of death in NI. Many of these deaths occur before 65 years of age and are potentially preventable since smoking, unhealthy diet, drinking in excess of the weekly drinking limits and physical inactivity are all major contributors to cardiovascular disease.

This section sets out the reviewed generic health improvement standards for health and social care. It includes clear quality requirements for care based on the best available evidence of what works most effectively for patients and clients.

Also included are performance indicators which will enable the monitoring of progress in implementing the standards by those organisations charged with their delivery: PHA, HSCB, Trusts and Primary Care.

In addition, this section sets out the new generic advocacy standard, which aims to ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.

Overarching standard 5: Healthy Eating (Generic)
All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.

Rationale:
Reducing fat and salt in the diet and increasing fruit and vegetable consumption is associated with a reduction in the risk of cardiovascular disease and hypertension.
Having a well balanced and nutritious diet will also help prevent many diseases which are linked to being overweight and obese such as high blood pressure, heart problems, risk of stroke, some cancers and Type 2 Diabetes. In addition, an improved diet can also contribute to an improvement in an individual's mental health and wellbeing.

Evidence:
WHO Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

Scientific Advisory Committee on Nutrition recommendations on healthy eating for the general population http://www.sacn.gov.uk/reports/

DHSSPS Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2012-2022)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

Quality Dimensions

Effective

All stakeholders should promote a consistent nutrition message by using the Eat Well – getting the balance right plate model. Training and education should be available for child carers / group care workers.

Person Centred

Lifeskills development programmes for young people should include input on tobacco as well as drugs, alcohol and solvents.

Performance Indicator:	Data source	Anticipated Performance Level	Date to be achieved by
Percentage of people eating the recommended 5 portions of fruit or vegetables each day	To be determined	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females Target: maintain or at best increase percentage by 1% year on year	

Overarching standard 6: Physical Activity (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.

Rationale:
The National Institute for Health and Clinical Excellence (NICE) has fully endorsed the importance of physical activity as a means of promoting good health and preventing disease. Lack of physical activity is associated with an increase in the risk of coronary heart disease.
The recently reviewed and updated UK Physical Activity Guidelines, supported by all four CMO's, provide advice and guidance on the recommended levels of physical activity throughout the life course. The report also presents the first time guidelines which have been produced in the UK for early years (under 5 year olds) as well as sedentary behaviour, for which there is now evidence that this is an independent risk factor for ill health.

Evidence:
WHO Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

National Institute for Health and Clinical Excellence (NICE) Public Health Intervention Guidance No.2 (2006) Four commonly used methods to increase physical activity: Brief intervention in primary care, exercise referral schemes, pedometers and community-based exercise programmes for walking and cycling http://www.nice.org.uk/Guidance/PH2

Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

DHSSPS Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2012-2022)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

New UK Physical Activity Guidelines UK physical activity guidelines : Department of Health - Publications

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

Quality Dimensions			
Effective Appropriate physical activity brief intervention training should be provided for Health and Social Care Staff to ensure clients receive consistent and timely advice.			
Performance Indicator: Percentage of people meeting the recommended level of physical activity per week	**Data source** Northern Ireland Health Survey	**Anticipated Performance Level** New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov/ Dec 2013. Performance level to be agreed thereafter	**Date to be achieved by** March 2014

Overarching standard 7: Smoking (Generic)
All Health and Social Care staff, as appropriate, should advise people who smoke of the risks associated with smoking and sign-post them to well-developed specialist smoking cessation services.

Rationale:
Smoking is a major risk factor for a number of chronic diseases including a range of cancers, coronary heart disease, strokes and other diseases of the circulatory system. Its effects are related to the amount of tobacco smoked daily and the duration of smoking.

A number of specialist smoking cessation services have been commissioned in a range of settings across Northern Ireland. These services offer counselling and support in addition to the use of pharmacotherapy by trained specialist advisors.

Evidence:
Tobacco Control Strategy for Northern Ireland – 2012-2022
http://www.dhsspsni.gov.uk/showconsultations?txtid=46925

NICE produced guidance on brief interventions and referral for smoking cessation in primary care and other settings in March 2006, which represents best practice http://www.nice.org.uk/Guidance/PH1

NICE guidance on 'Smoking Cessation Services, in primary care, pharmacies, local authorities and workplaces, particularly for manual working groups, pregnant women and hard to reach communities, February 2008
http://www.nice.org.uk/Guidance/PH10

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

<table>
<tr><th colspan="4">Quality Dimension</th></tr>
<tr><td colspan="4">Effective
Brief Intervention Training for Health and Social Care Staff will ensure clients receive consistent and timely advice on smoking cessation.
Specialist smoking cessation services will be delivered to regional quality standards ensuring equitable service provision.
People who are ready to stop smoking should be able to access specialist smoking cessation services in a choice of settings</td></tr>
<tr><td>Performance Indicator:</td><td>Data source</td><td>Anticipated Performance Level</td><td>Date to be achieved by</td></tr>
<tr><td>Number of people who are accessing Stop Smoking Services</td><td>ELITE (PHA Stop Smoking Services Performance Report)</td><td>Baseline 2011/12 = 39,204. 4 % year on year increase</td><td>March 2014
March 2015
March 2016</td></tr>
<tr><td>Proportion of the smoking population who are accessing Stop Smoking Services</td><td>ELITE (PHA Stop Smoking Services Performance Report)</td><td>Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target should be to maintain at >= 5%</td><td>March 2014
March 2015
March 2016</td></tr>
<tr><td>Number of people using stop smoking services who have quit at 4 weeks and 52 weeks</td><td>ELITE (PHA Stop Smoking Services Performance Report)</td><td>Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. 2% year on year increase from 11/12 baseline (20,299 – 4 weeks, 5,889 – 52 weeks)</td><td>March 2014
March 2015
March 2016</td></tr>
</table>

Overarching standard 8: Alcohol (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.

Rationale:
Excessive alcohol consumption is associated with many diseases such as cancers (oesophagus, liver etc), cirrhosis of the liver and pancreatitis. There are also direct effects of alcohol and an increased association with injuries and violence.

Excessive alcohol consumption can affect the cardiovascular system, and is associated with high blood pressure, abnormal heart rhythms, cardiomyopathy and haemorrhagic stroke.

Evidence:
SIGN: The Management of harmful drinking and alcohol dependence in Primary Care http://www.sign.ac.uk/pdf/sign74.pdf

New Strategic Direction for Alcohol and Drugs Phase 2 (2011 – 2016)
http://www.dhsspsni.gov.uk/new_strategic_direction_for_alcohol_and_drugs_phase_2__2011-2016_

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
HSC Trusts
Primary Care

Quality Dimension

Effective
Appropriate alcohol brief intervention training should be provided for Health and Social Care Staff to ensure clients receive consistent and timely advice.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people who receive screening in primary care settings in relation to their alcohol consumption	Northern Ireland Local Enhanced Service for Alcohol	Establish baseline Performance level to be determined once baseline established	March 2014

Overarching standard 9 – Safeguarding People (Generic)

All Health and Social Care staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.

Rationale:

A wide range of people, for a variety of reasons, have been shown to be at risk of harm through abuse, exploitation or neglect. People of all ages have the right to be safeguarded from such harm; to have their welfare promoted; and their human rights upheld. At the same time, they have the right to choose how to lead their lives, provided their lifestyle choices do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of themselves. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. In this Standard, the term safeguarding is intended to be used in its widest sense, that is, to encompass both **preventive** activity, which aims to keep people safe and prevent harm occurring, and **protective** activity, which aims to provide an effective response in the event that there is a concern that harm has occurred or is likely to occur.

All HSC staff and staff providing services on behalf of the HSC have a dual responsibility with regard to safeguarding: (a) to ensure that all service users are treated with respect and dignity and are kept safe from poor practice that could lead to harm; and (b) that all staff are alert to the indicators of harm from abuse, exploitation or neglect wherever it occurs and whoever is responsible; and know how and where to report concerns about possible harm from abuse, exploitation or neglect whether these relate to the workplace or the wider community.

Effective safeguarding can ensure that people are safeguarded and their welfare promoted whether in their own homes; in the community; in families; and in establishments such as children’s homes; secure accommodation; residential care and nursing homes; and hospitals.

Through safeguarding and in conjunction with positive engagement of individuals, (and as appropriate their family and carers) effective prevention and potential for early intervention is enhanced and promoted and care and service plans are supported to deliver better outcomes.

Where safeguarding is promoted, staff are empowered to act as advocates to safeguard vulnerable individuals and professional advocacy and counselling services are provided where required. A learning culture is also evident and staff are knowledgeable about safeguarding and keep abreast of local and national developments and learning, including enquiries, serious case reviews, case management reviews, inquiries and reports.

The quality of outcomes is more consistent, regardless of age, disability, gender, ethnic origin, religion, language, sexuality, political opinion, who pays for their care or their access to HSC provided or purchased services.

Application in the wider community of knowledge and expertise gained in the workplace serves to safeguard people more broadly and more generally.
The cycle of abusive behaviour(s) and/or neglect is broken.

Evidence:
European Convention on Human Rights http://www.hri.org/docs/ECHR50.html

The Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children
http://www.dhsspsni.gov.uk/index/hss/child_care/child_protection/child_protection_guidance.htm

UN Convention on the Rights of the Child
http://www2.ohchr.org/english/law/crc.htm

Council of Europe Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse
http://conventions.coe.int/Treaty/EN/treaties/html/201.htm

UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment http://www2.ohchr.org/english/law/cat-one.htm

A Guide to the Human Rights Act 1998: Third Edition (Department for Constitutional Affairs, London, October 2006)
http://www.justice.gov.uk/guidance/docs/act-studyguide.pdf

Improving the Patient & Client Experience 5 Standards: Respect, Attitude, Behaviour, Communication and Privacy and Dignity (DHSSPS, 2008)
http://www.dhsspsni.gov.uk/improving_the_patient_and_client_experience.pdf

Co-operating to Safeguard Children (DHSSPS, 2003) -
http://www.dhsspsni.gov.uk/show_publications?txtid=14022

Ageing in an Inclusive Society - Promoting the Social Inclusion of Older People (OFMDFM, 2005) currently under review http://www.ofmdfmni.gov.uk/ageing-strategy.pdf

Report of the Promoting Social Inclusion Working Group On Disability (OFMDFM, 2009) - access through: http://www.ofmdfmni.gov.uk/disability-promoting-social-inclusion

A Life Like Any Other? Human Rights of Adults with Learning Disabilities (The Joint Committee on Human Rights, Seventh Report of Session 2007-08 Volume 1) - http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/4002.htm

European report on preventing elder maltreatment (World Health Organisation, 2011) - http://www.euro.who.int/en/home

Responsibility for delivery / implementation

HSC Board & Local Commissioning Groups
Public Health Agency
HSC Trusts
Primary Care and Contracted Services
Patient and Client Council
Regulation and Quality Improvement Authority
Safeguarding Board for Northern Ireland (SBNI) & Safeguarding Panels
Northern Ireland Adult Safeguarding Partnership (NIASP) & Local Adult Safeguarding Partnerships (LASPs)
Working in partnership with the Police Service of Northern Ireland and other criminal justice agencies
Working in partnership with other statutory agencies and the Voluntary, Community and Private Sectors

Quality Dimensions

Safe

Promotion of self-aware practice; supportive of person-centred engagement; fosters awareness and opportunity for early intervention in poor practice/potentially abusive dynamics; and promotion of individualised safety plans where these are indicated, thereby enhancing services and safeguarding awareness and responses.

Effective

Promotion of self-reliance and personal and professional safeguarding behaviours; builds personal and professional safeguarding capacity; promotion of the welfare of individuals; protection from mistreatment; impairment of health and development is prevented; and individuals are kept safe from harm.

A better focus on prevention reduces poor practice; promotes recovery; reduces complaints; breaks the cycle of abusive behaviour and/or neglect; and reduces or removes the need to have recourse to emergency services.

Person-Centred
Safeguarding interventions must be tailored to the presenting circumstances and to the needs and choices of the individual (provided these do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of him or herself) and his/her circumstance. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. Safeguarding responses are non-discriminatory, and seek to ensure that people of all ages at risk of harm are offered support to keep them safe from harm and to protect them when harm occurs. Services are better able to support individuals, families and carers thereby aiding improvement of relationships; and to help perpetrators to address their behaviours.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
All HSC Organisations and organisations providing services on behalf of the HSC have a Safeguarding Policy in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc). The Safeguarding Policy is supported by robust procedures and guidelines	HSC and provider Organisation annual reports HSC Governance Reviews, e.g. Complaints; SAIs, etc HSC Statutory Functions Reports and Corporate Parent Reports SBNI, NIASP & LASP Annual Reports	Establish baseline Performance level to be determined once baseline established	March 2014
All HSC Organisations and organisations providing services on behalf of the HSC have Safeguarding Plans in place	RQIA Reports & Reviews Case Management Reviews (CMRs)	Establish baseline Performance level to be determined once baseline established	March 2014
All HSC Organisations and organisations providing services on behalf of the HSC have safeguarding champions in place to promote awareness of safeguarding issues in their workplace	Serious Case Reviews (SCRs)	Establish baseline Performance level to be determined once baseline established	March 2014

SECTION 6 – STANDARDS FOR SPECIFIC CONDITIONS

6.1 CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Chronic obstructive pulmonary disease is a common lung disease with 34,522 people recorded on GP registers in Northern Ireland as having COPD. It is caused in nearly all cases by long term cigarette smoking. Smoking can lead to damaged airways in the lung, causing cough and phlegm and making the airways narrower, so making it more difficult to breathe. The diagnosis is confirmed by spirometry, a simple breathing test carried out by blowing into a machine which can show if the airways have narrowed. The best way of preventing the progression of COPD is to stop smoking.

Drug therapy can help in COPD. Bronchodilators are drugs which widen the airways. There are different types of bronchodilators which work in different ways and can be used together. They are usually given through an inhaler device or very occasionally by nebuliser.

The symptoms of COPD sometimes worsen. These episodes are known as exacerbations and may be treated with short courses of antibiotics and corticosteroids.

Pulmonary rehabilitation can also improve the symptoms of COPD. This is a programme of supervised exercise as well as discussions with health care professionals and other patients to help understand COPD and its treatment.

In some circumstances hospital admission may be necessary. In a very severe exacerbation the person may require assistance with their breathing. This can usually be achieved by the technique of non-invasive ventilation (NIV). This is carried out by placing a mask over the nose and mouth. The mask is connected to a small machine, which pushes air through the mask and into the person’s lungs. This treatment should be set up and monitored by a team of health professionals with appropriate training and experience.

After assessment and stabilisation in hospital, people may be discharged onto an early discharge scheme delivered by a respiratory team working within the community. This community respiratory specialist team can also provide case management, which allows for more follow-up within the community setting.

Some people will require assessment as to whether they may benefit from continuous oxygen treatment, known as long term oxygen therapy (LTOT) or the use of oxygen during exercise.

In some cases COPD can progress and cause shortness of breath which does not respond well to drug treatment. Specialist respiratory teams should be available to help deal with the palliative care needs of these people and those of their carers.

Overarching Standard 10:
All people suspected of having COPD should have accurate early diagnosis, assessment and management in primary care.

Rationale:
COPD should be prevented where possible, but, as a minimum, disease progression should be slowed down or avoided by early diagnosis and optimal management in keeping with the most up to date evidence based guidelines.

Evidence:
CG101 Chronic obstructive pulmonary disease (update): NICE guideline - 2010
http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011
http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

COPD: Supporting tool for the Implementation of National Guidance (Medicines Management Committee) - 2012
http://primarycare.hscni.net/pdf/COPD_Supporting_Tool_Final_May_2012.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Intergrated Care Partnerships (ICPs)

Quality Dimensions

Safe
Spirometry should be carried out on calibrated equipment by health care professionals competent in its performance and interpretation.

Accessible
Early diagnosis of COPD improves outcomes. All people older than 35 years, with past/present smoking history, and presenting with exertional breathlessness, chronic cough, regular sputum production, frequent winter bronchitis or wheeze should have spirometry performed.

Effective
People with COPD should be offered inhaled and oral therapies, in accordance with NICE (2010) guidance and their degree of functional breathlessness as part of an individualised comprehensive management plan.

Efficient
All people suspected of or diagnosed with COPD should have their smoking history recorded and be given appropriate advice about smoking cessation and specialist smoking cessation services.

Equitable
All people with a diagnosis of COPD should be offered an assessment and review according to NICE guidelines.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of GP practices that develop a register of people who are smokers and/or ex-smokers, over 35 and on short acting beta agonists to facilitate case finding for COPD.	Regional LES	All practices to have developed registers	March 17
Percentage of people with COPD (diagnosed on or after 1 April 2011) in whom the diagnosis has been confirmed by post bronchodilator spirometry between 3 months before and 15 months after entering on to the register.	QOF	60% 80%	March 16 March 17
Percentage of people with COPD with a record of FEV_1 in the preceding 15 months.	QOF	75%	March 17
Percentage of people with COPD who have had a review, undertaken by a healthcare professional, including an assessment of breathlessness using the Medical Research Council dyspnoea scale in the preceding 15 months.	QOF	70% 90%	March 16 March 17
Percentage of people with a diagnosis of COPD and an MRC breathlessness score of >3 and/or functional breathlessness who have been referred for pulmonary rehabilitation.	Regional LES	70%	March 17

Percentage of people with COPD and Medical Research Council dyspnoea grade greater/equal to 3 at any time in the preceding 12 months, with a record of oxygen saturations value within the preceding 15 months.	QOF	70% 90%	March 16 March 17
Percentage of people with COPD with Sp02 levels <92% who are referred to the local Home Oxygen Assessment and Review (HOS-AR) service.	Regional LES	90%	March 17
Percentage of people with COPD who smoke, who have had appropriate smoking advice.	Regional LES	90% 95%	March 16 March 17
Percentage of people with COPD who have had influenza immunisation in the preceding 1 Sept to 31 March.	QOF	95%	March 16

Overarching Standard 11 – Specialist community team care

All people with COPD who meet the referral criteria should have access to the services provided by specialist respiratory teams in the community.

Rationale:

All people should have access to the full range of specialist care in the community to improve quality of life, optimise outcomes and avoid unnecessary admissions. This includes the following:

- Enhanced supported self-management as part of case management;
- Manage exacerbations;
- Pulmonary rehabilitation;
- Oxygen assessment;
- Nebuliser assessment;
- Supported discharge and follow-up;
- Palliative care.

This would usually include those with severe / very severe disease, as well as some people with moderate disease who may have frequent exacerbations and require post-discharge management.

Evidence:

CG101 Chronic obstructive pulmonary disease (update): NICE guideline
http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011
http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Community specialist respiratory teams
Integrated Care Partnerships (ICPs)

Quality Dimensions

Accessible
Specialist care should be available in the community, with access when required, 7 days a week.

Efficient
Identifying people at risk of exacerbation and providing care can prevent emergency admissions.

Equitable
Specialist community respiratory teams should be available in all parts of Northern Ireland.

Person Centred
Treatment and care should take into account peoples individual needs and preferences.

Performance Indicator:	Data Source	Anticipated Performance Level	Date to be achieved by
Percentage of people with severe/very severe COPD who are under the care of the Specialist Community Respiratory Team.	Regional LES (To be agreed)	Baseline to be established Performance levels to be determined	March 17 March 18

Overarching Standard 12 – Self-management
All people with COPD and their carers should be given the opportunity to learn about their disease. Those meeting the criteria for pulmonary rehabilitation and case management should receive enhanced supported self-management as part of their care.

Rationale:
People with COPD and their carers should be given greater control over their lives by ensuring that knowledge of their condition is developed to a point where they can take responsibility for its management and enabled to work in partnership with their health and social care providers.

The evidence base suggests that limited self-management education, without a multi-faceted self-management programme or on-going case management is less effective in improving health-related quality of life and reducing health care resource utilisation.

Evidence:
CG101 Chronic obstructive pulmonary disease (update): NICE guideline – 2010 http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011 http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

Cochrane review: Self-management education for patients with chronic obstructive pulmonary disease. Effing, Monninkhof et. al (2009) http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD002990.pub2/pdf/abstract

Cochrane Review: Action plans with limited patient education only for exacerbations of chronic obstructive pulmonary disease. Walters, Turnock et al (2010) http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD005074.pub3/pdf/abstract

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions

Effective
People with COPD should develop self-management action plan in conjunction with their health profession which supports them to respond promptly to the symptoms of an exacerbation. This should incorporate the use of antibiotics and steroids for those who have had a previous exacerbation and are identified as likely to benefit, which incorporates a contact number in and out of hours.

Person Centred
Those with COPD should be given the opportunity to learn about all aspects of the disease process and receive information on the:

- Nature of the disease
- Rationale for symptoms experienced
- Description of treatments and their function
- Treatment options
- Identification and avoidance of risk factors

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people with COPD given individualised, face to face information and a written self-management action plan.	Regional LES	90% 95%	March 16 March 18
Percentage of people attending pulmonary rehabilitation programmes who have received individualised, face-to-face information and an updated written self-management action plan.	Trust report	70% 90%	March 16 March 18
Percentage of people with COPD receiving case management from specialist community respiratory teams who have received individualised, face-to-face information and an updated written self-management action plan.	Trust report	70% 90%	March 16 March 18

Overarching Standard 13 – Management of acute exacerbations

All people with an acute exacerbation of COPD should be managed to an optimal standard in an appropriate setting.

Rationale:

Exacerbations of COPD may require different management strategies, according to severity.

Evidence:

CG101 Chronic obstructive pulmonary disease (update): NICE guideline - 2010
http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011
http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

Northern Ireland Management of Infection Guidelines for Primary Care (2013) – Acute Exacerbation of COPD section
http://www.dhsspsni.gov.uk/infection_guidelines_2013.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimension

Safe
All people who are admitted to hospital should be seen by a member of the specialist respiratory team (respiratory nurse specialist / respiratory physiotherapy specialist / respiratory physician / SpR, staff grade or consultant).

Accessible
All people should have timely access to an assessment by their GP and community specialist respiratory team, as appropriate.

Effective
All people with an exacerbation of COPD should be assessed and managed according to NICE guidance.

Efficient
People who are appropriate for community management should be facilitated to be cared for at home.

Person Centred
People's individual needs and preferences should be taken into account when deciding location of care.

Performance Indicator:	Data Source	Anticipated Performance Level	Date to be achieved by
Percentage of GP practices with a red flag system to identify people presenting with an acute exacerbation of COPD in GP practices, OoH, emergency departments or ambulatory care settings.	Regional LES (to be agreed)	Baseline to be established	March 17
		Performance levels to be determined	March 18
Percentage of people with an acute exacerbation of COPD presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode	Regional LES (to be agreed)	Baseline to be established	March 17
		Performance levels to be determined	March 18

by the GP, practice nurse, community or secondary care.			
Percentage of people with COPD admitted to hospital for more than 24 hours with an exacerbation who receive care from a respiratory team.	Regional Discharge Audit / PAS	70% 90%	March 16 March 18
Percentage of people managed in a respiratory ward or formally designated respiratory area within a ward.	Regional Discharge audit / PAS	50% 70%	March 16 March 18
Smoking status should be documented on all people admitted with an exacerbation of COPD and advice on smoking cessation offered and documented.	Regional Discharge audit	70% 90%	March 16 March 18

Overarching Standard 14 – Non-invasive ventilation
All people with COPD with acute and/or chronic type 2 respiratory failure should have timely access to ventilatory support, if required, in a unit supervised by a respiratory physician or intensive care physician.

Rationale:
Non-invasive ventilation (NIV) should be used as the treatment of choice for persistent hypercapnic ventilatory failure despite optimal medical therapy. There is evidence that it reduces the need for admission to intensive care, reduces length of stay and improves survival.

Evidence:
CG101 Chronic obstructive pulmonary disease (update): NICE guideline - 2010
http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011
http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

Non-invasive ventilation in chronic obstructive pulmonary disorder: management of acute type 2 respiratory failure RCP/BTS Concise guideline – 2008
http://www.brit-thoracic.org.uk/Guidelines/NIPPV-NIV-in-Acute-Respiratory-Failure-Guideline.aspx

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts

Quality Dimensions			
Safe All health care professionals in respiratory wards should have the necessary competencies in the delivery of acute NIV. **Accessible** People admitted to hospital with an exacerbation of COPD and with persistent acidotic ventilatory failure are promptly assessed. **Effective** People with an acute exacerbation of COPD who are found to have respiratory acidosis (pH<7.35) despite delivery of controlled oxygen therapy and maximal medical treatment should be assessed for non-invasive ventilation. **Equitable** All hospitals receiving acute medical admissions should have facilities on site and trained staff available for non-invasive ventilation 24 hours per day, 7 days per week.			
Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people admitted with an exacerbation of COPD who have had an arterial blood gas (ABG) assessment on admission to identify ventilatory failure.	BTS NIV audit	90% 95%	March 16 March 18
Percentage of people who receive non-invasive ventilation in a respiratory ward or dedicated formally designated respiratory area within a ward.	BTS NIV audit / PAS	90% 95%	March 16 March 18
Percentage of people who receive non-invasive ventilation who have a clear management plan which includes ceiling of care.	BTS NIV audit	90% 95%	March 16 March 18

Overarching Standard 15: Supported discharge
All people admitted to hospital with acute exacerbations of COPD should receive appropriate discharge planning and follow-up.

Rationale:
The European British Thoracic Society COPD audit showed that Northern Ireland has a median readmission rate of 43% at 90 days. It is important to have appropriate discharge planning and post-discharge support to prevent unnecessary readmissions.

Evidence:
CG101 Chronic obstructive pulmonary disease (update): NICE guideline - 2010
http://guidance.nice.org.uk/CG101

NICE Quality Chronic Obstructive Pulmonary Disease Standards – 2011
http://publications.nice.org.uk/chronic-obstructive-pulmonary-disease-quality-standard-qs10/list-of-statements

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Hospital and community specialist respiratory teams

Quality Dimensions

Safe
Early discharge should only be implemented when there are adequate support mechanisms from respiratory specialists and access to social care in the community.

Accessible
Post discharge follow-up should occur within 48-72 hours of discharge.

Effective
Pulmonary rehabilitation for those who fulfil inclusion criteria should be available within 2 weeks of discharge.

Efficient
There should be systems to support people to be effectively managed at home if this is deemed appropriate.

Performance Indicator:	**Data Source**	**Anticipated Performance level**	**Date to be achieved by**
Percentage of people discharged from hospital following admission for an exacerbation of COPD who have the following aspects of the COPD discharge bundle completed: • smoking cessation advice • individualised self-management plan • inhaler technique checked • referral to pulmonary rehabilitation • referral to community team for assessment and review for more complex needs	COPD discharge care bundle audit	70% 90%	March 16 March 18
Percentage of people discharged from hospital following admission for an exacerbation of COPD who have been offered access to rapid pulmonary rehabilitation within 4 weeks of discharge (providing they fulfil the inclusion criteria).	COPD discharge care bundle audit	40% 60%	March 16 March 18

6.2 OXYGEN THERAPY IN COPD

People with severe lung problems may have low levels of oxygen in their blood, which can make them feel tired and breathless. If this is the case, breathing in extra oxygen via special equipment may help. When this is recommended for long periods every day it is known as long-term oxygen therapy.

Not everyone with lung problems will benefit from oxygen, as there are many causes of breathlessness other than low oxygen levels. It is important that people are assessed by an expert in lung conditions before they receive oxygen therapy, to make sure that it is the right treatment for them, and to check that there are no other causes of their symptoms that need treated.

If it is recommended that a person receives oxygen therapy at home, it is important that they get all the information and training they need to use the equipment safely. They should also know who they need to contact if they have any concerns. The equipment should be checked by a professional regularly to make sure it is working, and the person should be reviewed regularly to check that the oxygen is helping them.

Overarching standard 16:
All people requiring long term oxygen therapy (LTOT) are appropriately assessed prior to commencement of therapy.

Rationale:
Long term oxygen therapy (LTOT) improves survival and reduces hospital admissions in people with a respiratory condition who are hypoxic

Evidence:
National Institute for Health and Care Excellence (NICE)(2010) Chronic Obstructive Pulmonary Disease (update)
http://guidance.nice.org.uk/CG101/Guidance/pdf/English

NICE Quality Standard (2011) Initial assessment for long term oxygen therapy
http://www.nice.org.uk/guidance/qualitystandards/chronicobstructivepulmonarydisease/initialassessmentforlongtermoxygentherapy.jsp

Royal College of Physicians (1999) Domiciliary Oxygen Therapy Clinical guidelines
http://www.rcplondon.ac.uk/sites/default/files/documents/domiciliary-oxygen-therapy-services.pdf

British Thoracic Society (2006) Clinical component for the home oxygen service in England and Wales
http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Home%20Oxygen%20Service/clinical%20adultoxygenjan06.pdf

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Home Oxygen Service – Assessment & Review (HOS-AR) service
Primary care

Quality Dimensions

Safe

- Long term oxygen therapy aims to improve survival in people with COPD who have severe hypoxaemia (PaO2 < 8kPa) as well as reducing the incidence of polycythaemia, reducing the progression of pulmonary hypertension and improving neuropsychological health.
- The assessment of people for LTOT should comprise the measurement of arterial blood gases on two occasions at least 3 weeks apart in those who have a confident diagnosis of COPD, who are receiving optimum medical management and whose COPD is stable.

Accessible

- There should be no unnecessary delays between the decision that LTOT is required and the commencement of therapy.

Effective

- All management should comply with current available evidence.

Efficient

- People deemed to be at high risk should be prioritised for assessment.

Equitable

- There should be equal access to high quality care and appropriate assessment for all people requiring LTOT.

Person Centred

- All people on LTOT are actively involved in decisions relating to their oxygen treatment and the mode of delivery. Due consideration should be given to balancing the clinical benefit of treatment with patient choice, taking due regard of the individual’s needs and wishes.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of Trusts that have HOS-AR assessment processes in place for LTOT.	HSC Trust report	All Trusts	March 16
Percentage of people started on LTOT who have been appropriately assessed via the assessment process.	HOS database	Baseline to be established Performance levels to be determined	March 16 March 17

Overarching standard 17

Ambulatory oxygen therapy should be prescribed for all people already on LTOT who wish to continue with oxygen therapy outside the home, and who are prepared to use it, but only after an appropriate assessment has been performed by a specialist.

Rationale:

The provision of ambulatory oxygen for people whose resting oxygen is normal but who desaturate on activity and for those on LTOT enables them to leave their home for short periods of time. This has positive benefits such as increased activity, independence and quality of life; interaction with the world around them and feeling connected to their community.

Evidence:

National Institute for Health and Care Excellence (NICE)(2010) Chronic Obstructive Pulmonary Disease (update)
http://guidance.nice.org.uk/CG101/Guidance/pdf/English

NHS Primary Care Commissioning: Home Oxygen Service – Assessment and Review (April 2011)
http://www.improvement.nhs.uk/lung/GoodPracticeGuides/Homeoxygenservice/tabid/193/Default.aspx

Royal College of Physicians (1999) Domiciliary Oxygen Therapy Clinical guidelines
http://www.rcplondon.ac.uk/sites/default/files/documents/domiciliary-oxygen-therapy-services.pdf

British Thoracic Society (2006) Clinical component for the home oxygen service in England and Wales
http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Home%20Oxygen%20Service/clinical%20adultoxygenjan06.pdf

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Home Oxygen Service – Assessment & Review (HOS-AR) service
Primary care

Quality Dimensions

Safe
Ambulatory oxygen therapy can be used as a way of ensuring that people who require long term oxygen therapy and who leave the home on a regular basis receive oxygen for sufficient hours to gain the benefits of LTOT.

Accessible
There should be no unnecessary delays between the request for ambulatory oxygen and the provision of ambulatory oxygen for those people in whom it would be appropriate.

Effective
All management should comply with current evidence available.

Efficient
People deemed to be at high risk should be prioritised for assessment. Those people identified as potentially deriving greatest benefit from ambulatory oxygen should be assessed promptly.

Equitable
There should be equal access to high quality care for all people**.**

Person Centred
All people on LTOT are actively involved in decisions relating to their oxygen treatment and the mode of delivery. Due consideration should be given to balancing the clinical benefit of treatment with patient choice, taking due regard of peoples needs and wishes.

Performance Indicator:	**Data source**	**Anticipated performance levels**	**Date to be achieved by**
Percentage of Trusts that have HOS-AR assessment processes in place for ambulatory oxygen.	HSC Trust report	All Trusts	March 16
Percentage of people prescribed ambulatory oxygen in addition to LTOT via a concentrator following specialist assessment.	HOS database	Baseline to be established Performance levels to be determined	March 16 March 17

Overarching standard 18
All people commenced on long term oxygen therapy have their condition reviewed at least annually by a specialist oxygen service (HOS-AR)

Rationale:
Home oxygen should not be prescribed on a long-term basis unless a clinical assessment has been undertaken. Where long term oxygen is prescribed, a review should be undertaken by a specialist oxygen service at least annually to ensure that people continue to derive a clinical benefit.

Evidence:
National Institute for Health and Care Excellence (NICE)(2010) Chronic Obstructive Pulmonary Disease (update)
http://guidance.nice.org.uk/CG101/Guidance/pdf/English

Quality Standard
http://www.nice.org.uk/guidance/qualitystandards/chronicobstructivepulmonarydisease/reviewoflongtermoxygentherapy.jsp

Royal College of Physicians (1999) Domiciliary Oxygen Therapy Clinical guidelines
http://www.rcplondon.ac.uk/sites/default/files/documents/domiciliary-oxygen-therapy-services.pdf

British Thoracic Society (2006) Clinical component for the home oxygen service in England and Wales
http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Home%20Oxygen%20Service/clinical%20adultoxygenjan06.pdf

NHS Primary Care Commissioning (2011) Home oxygen service - assessment and review good practice guide
http://www.improvement.nhs.uk/lung/GoodPracticeGuides/Homeoxygenservice/tabid/193/Default.aspx

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Home Oxygen Service – Assessment & Review (HOS-AR) service
Primary care

Quality Dimensions

Safe

- The overarching aim is to ensure people continue to receive benefit from their long-term oxygen therapy.

- People prescribed oxygen and clinicians alike should be well informed about the nature, scope and capability of the home oxygen service. The service should:
  - Have quality at its core: in other words, be accessible, safe, effective and responsive to people;
  - Be evidence-based, clinically-led and continually strive to improve outcomes for people; and
  - Be affordable and represent good value for money.

Accessible

- People receiving LTOT should be reviewed at least once per year by practitioners familiar with LTOT and this review should include pulse oximetry.

Effective

- All management should comply with current available evidence.

Efficient

- People deemed to be at high risk should be prioritised for review. A HOS-AR service should be established.

Equitable

- There should be equal access to high quality care and management for all people on LTOT.

Person Centred

- All people on LTOT are actively involved in decisions relating to their oxygen treatment and the mode of delivery. Due consideration should be given to balancing the clinical benefit of treatment with patient choice, taking due regard of people's needs and wishes.

Performance Indicator	**Data source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of people on LTOT who have had their condition reviewed by a specialist HOS-AR service in the last 12 months.	Trusts HOS -AR clinics	Baseline to be established	March 16
		Performance levels to be determined	March 17

Overarching standard 19
All people with COPD should be treated with appropriate controlled oxygen therapy during transportation in ambulances

Rationale:
People with COPD who become hypoxic should have their hypoxia corrected with oxygen therapy during transport. However, some of these people can develop acute hypercapnic respiratory failure if excessive oxygen is administered.

Evidence:
National Institute for Health and Care Excellence (NICE)(2010) Chronic Obstructive Pulmonary Disease (update)
http://guidance.nice.org.uk/CG101/Guidance/pdf/English

British Thoracic Society (2008) Guideline for emergency oxygen use in adult patients
http://www.brit-thoracic.org.uk/Guidelines/Emergency-Oxygen-use-in-Adult-Patients.aspx

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Home Oxygen Service – Assessment & Review (HOS-AR) service
Primary care

Quality Dimensions

Safe
People with COPD who become hypoxic should have their hypoxia corrected with oxygen therapy during transport. However, some of these people can develop acute hypercapnic respiratory failure if excessive oxygen is administered.

Effective
All management should comply with current available evidence.

Performance Indicator	Data source	Anticipated performance levels	Date to be achieved by
Percentage of people with a history of hypercapnic respiratory failure issued with an Oxygen Alert Card and a 24% or 28% Venturi mask and Ambulance Control informed.	Trust report	Baseline to be established Performance levels to be determined	March 16 March 17

6.3 ASTHMA IN ADULTS

Asthma is a common disease in Northern Ireland with over 115,000 people on GP registers recorded as having asthma. This disease affects the bronchi, which are the tubes carrying air in and out of the lungs. People with symptomatic asthma have bronchi which are almost always red and sensitive (inflamed). When a person with asthma comes into contact with something that irritates his or her airway (an asthma trigger), the muscles around the walls of the airway tighten so that the airways become narrower and the lining of the airways become inflamed and start to swell.

When asthma is well controlled, quality of life improves and this allows people to do the things they want to do. Treatment is available for all people with asthma although for a small number of cases it may be less effective.

Self-management involves supporting people with asthma to learn about their condition, recognise when their asthma is getting worse and know what action to take. There is good quality research to show that when self-management is combined with seeing your doctor or asthma nurse regularly and a written individualised self-management asthma action plan, it can help people with asthma to stay healthier, feel in control of their condition and be less likely to need to go to hospital.

People with difficult and severe asthma can have unpredictable severe asthma attacks which occur without warning, resulting in them being admitted to hospital quite frequently. They may also need regular or frequent courses of steroid tablets to treat their symptoms.

It is essential, therefore, that all people with asthma are appropriately assessed, diagnosed, informed, treated and reviewed regularly, according to the severity of their condition.

The standards set out below outline the standard of care that people with asthma and their carers should expect to receive. The standards specify what is required in relation to:

- The appropriate assessment and investigations for those people suspected as having asthma;
- The information which people with asthma should receive to enable them to self-manage their condition, and,

- The treatments, therapies and management which people with asthma, difficult asthma and severe acute asthma should have available to them.

It is important, therefore, that people with asthma and their carers are aware of these standards and use them to their advantage to help manage their condition and improve their quality of life.

Each standard is underpinned with a rationale and evidence from various organisations which have carried out research in these areas for the proposed action together with clear statements about the expected quality aspects which are required for each of the actions.

Much work has gone into developing these standards and it is hoped that they will benefit both health and social care professionals and people with asthma, to improve the health and wellbeing of people with asthma.

Overarching Standard 20 – Diagnosis of Asthma
All people with suspected asthma should have assessment and investigations to confirm the diagnosis.

Rationale:
Any individual with symptoms suggestive of asthma should be investigated in line with BTS/SIGN guidance and have a robust diagnosis before committing them to prolonged treatment for this condition. It is important that the diagnostic process is clearly documented to ensure that people with asthma receive the most appropriate management. It is important to consider the possibility of occupational asthma, as identification and removal of occupational triggers can be potentially curative in these cases.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually] http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions

Safe

- All staff performing and interpreting spirometry should have undergone appropriate quality assured spirometry training.
- In primary care, relevant practice staff must be appropriately trained to meet modern authoritative standards. Training needs of staff should be reviewed regularly in line with recommendations from HSCB.

Effective

- All people with a clinical diagnosis of asthma should have:
  - A clinical history and examination consistent with the diagnosis of asthma and not suggestive of an alternative condition.
  - Where possible objective lung tests e.g. spirometry should be undertaken at the time of suspected diagnosis and interpreted according to BTS/SIGN guidelines.
  - A documented clinical response to asthma treatment.
- Adults with new onset asthma should be assessed for occupational causes.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people aged 8 or over with asthma (diagnosed on or after 1 April 2006) on the register with measures of variability or reversibility recorded between 3 months before or any time after diagnosis. (QOF AST indicator 002)	QOF	80%	March 16

Overarching Standard 21 – Self-management
All people with asthma and their carers should be given the opportunity to learn about their condition and receive a written individualised self-management asthma action plan.

Rationale:
There is high quality clinical trial evidence supporting the use of personalised action plans in the self-management of asthma to improve asthma outcomes, including patient self-efficacy and confidence as well as hospital admission rates. The evidence for written, personalised action plans is strongest when given as part of a structured education programme and combined with regular practitioner review.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Cochrane Review: Self-Management, education and regular practitioner review for adults with asthma (Gibson, Powell et al. 2009)
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001117/abstract

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships

Quality Dimensions

Effective

- Written individualised asthma self-management action plans should be discussed face-to-face with the person and include:
    - How to recognise and manage deterioration in condition
    - How and when to seek appropriate medical help
    - Contact numbers for named health professionals
- All people with asthma who smoke should have their smoking status recorded, be offered appropriate smoking cessation advice and access to specialist smoking cessation services.

Person Centred

- All people with asthma should be given the opportunity to learn about all aspects of the disease process to include the nature of the disease, rationale for symptoms experienced, description of treatments and their function, treatment options, and help with the identification and avoidance of risk/trigger factors.
- Where appropriate, families / carers should be involved, especially where the person with asthma may have reduced capacity for example, learning disability and dementia.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people with asthma step 2 and above who have had individualised face to face information and written self-management action planning	Regional LES	80%	March 16
Number of people aged over 15 with newly diagnosed asthma step 2 or above, who have attended and completed an asthma specific structured education programme (Long term conditions programme)	Programme providers	Baseline to be established Performance levels to be determined	March 16 March 17

Overarching Standard 22 – Ongoing management
All people with asthma should be on appropriate pharmacological therapy according to the nature and severity of their disease.

Rationale:
In the majority of cases, asthma is a treatable condition if currently available therapies are targeted appropriately, giving people with asthma good control of symptoms and excellent quality of life.

Allergic rhinitis affects 10-25% of the population and has a direct relationship with asthma. Good rhinitis control contributes positively to asthma control.

Young people and adults who have asthma (mild or moderate) in association with an allergy are at particular risk of developing life threatening exacerbations of asthma. They should be monitored very closely on transition from paediatric services.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually] http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

National Institute for Health and Clinical Excellence (NICE) Corticosteroids for the treatment of chronic asthma in adults and children aged 12 years and over (2008) http://guidance.nice.org.uk/TA138

Bousquet J, Van Cauwenberge P, Khaltaev N, *et al*. Allergic Rhinitis and its Impact on Asthma (ARIA) in collaboration with the World Health Organization (WHO). J Allergy Clin Immunol 2001; 108 (Suppl):S147-S336. http://linkinghub.elsevier.com/retrieve/pii/S0091674901624886

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimension			
Effective • All people with a confirmed clinical diagnosis of asthma should have step-wise pharmacological management according to BTS/SIGN Guidelines. • All people with asthma should have their disease control assessed using a validated asthma control questionnaire; and taking into account their use of short acting bronchodilators; and the frequency of exacerbations requiring oral steroids. • All people should be asked to demonstrate their inhaler technique as appropriate. • All people with a clinical diagnosis of asthma either fulfilling the criteria for specialist referral in BTS/SIGN Guidelines or with difficult to control asthma (all those on step 5 treatment) should be appropriately referred for specialist respiratory physician assessment. • People with an established diagnosis of asthma should be appropriately evaluated for symptoms of allergic rhinitis.			
Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people with asthma, on the register, who have had an asthma review in the preceding 15 months that includes an assessment of asthma control using the 3 RCP questions.	QOF	70%	March 16
Percentage of people on step 5 treatment currently under the care of secondary care asthma services.	Regional LES	Baseline to be established Performance levels to be determined	March 16 March 17

Overarching Standard 23 – Management of acute severe asthma
All people with acute severe asthma should be accurately assessed and managed appropriately according to the severity of their presentation.

Rationale:
Acute severe asthma can be a life threatening condition. Confidential enquiries into asthma deaths have identified poor recognition or assessment of deterioration by both patients and health care providers as a potential contributory factor, emphasising the importance of prompt and accurate assessment of this condition.

The current NICE quality standards for asthma recommend that people with asthma who present with an exacerbation of their symptoms receive an objective measurement of severity at the time of presentation. A Northern Ireland audit of management has highlighted areas for improvement in the management of acute exacerbations.

If an individual requires emergency management for an acute exacerbation of asthma, it is important that they are reviewed to consider their on-going management to ensure they are receiving optimal therapy.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimension

Safe

- All people presenting with acute severe asthma must be appropriately and rapidly assessed according to BTS/SIGN Guidelines.
- All people with acute severe asthma must be managed according to the severity of their condition according to BTS/SIGN Guidelines.
- All people with acute severe asthma should be followed up by a GP or hospital clinician after an acute episode.
- All hospitals should have established 'red flag' systems, alerting GPs as to the possible need for follow up after treatment at ED with an acute exacerbation.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people with acute severe asthma presenting to ED or OoH* who have a post bronchodilator PFR carried out. **only those people requiring to be nebulised in OoH*	OoH audit	40% 50%	March 16 March 17
	ED audit	70% 80%	March 16 March 17
Percentage of people presenting with acute severe asthma to ED or OoH* who have an oxygen saturation of less than 94% who have a post bronchodilator oxygen saturation carried out and result recorded. **only those people requiring to be nebulised in OoH*	OoH audit	60% 80%	March 16 March 17
	ED audit	60% 80%	March 16 March 17
Percentage of GP practices with a red flag system to identify people presenting with acute severe asthma in GP practices, OoH, emergency departments or ambulatory care settings.	Regional LES to be agreed	Baseline to be established	March 17
		Performance levels to be determined	March 18

Percentage of people with acute severe asthma presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode by the GP, practice nurse, community or secondary care.	Regional LES to be agreed	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of practices with a register of people at risk of near fatal asthma.	Regional LES	70%	March 17
Percentage of people with acute severe asthma who are managed in a respiratory ward or formally designated respiratory area within a ward.	PAS	80% 90%	March 16 March 18
Percentage of people with acute severe asthma admitted to hospital with an exacerbation who received care from a respiratory team.	BTS audit	60% 80%	March 16 March 18
Percentage of people admitted with acute severe asthma on beta-2-agonist therapy only who are commenced on inhaled corticosteroids.	BTS audit	80% 90%	March 16 March 18
Percentage of people admitted with acute severe asthma who receive a written discharge care plan.	BTS audit	60% 80%	March 16 March 18

Overarching Standard 24 – Management of difficult asthma at secondary and tertiary level
All people with 'difficult asthma'* should be assessed and managed by a team with the appropriate skills and experience.

*'Difficult asthma' is defined as those who are symptomatic on BTS/SIGN guidelines step 4 treatment and all people on step 5 treatment.

Rationale:
In those with difficult to control asthma, there may often be other factors contributing to sub-optimal symptom control such as poor adherence to medication, alternative or coexistent diagnoses and psychological comorbidity. Systematic multidisciplinary assessment and management results in improved outcomes for these people. A proportion of people will have refractory disease, which is relatively resistant to standard therapies but who may be suitable for treatment with new monoclonal antibody therapy.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

NHS England 2013/14 Standard Contract for Respiratory: Severe Asthma
http://www.england.nhs.uk/resources/spec-comm-resources/npc-crg/group-a/a14/

NICE Technology Appraisal: TA278 Omalizumab for treating severe persistent allergic asthma (review of technology appraisal guidance 133 and 201)
http://publications.nice.org.uk/omalizumab-for-treating-severe-persistent-allergic-asthma-review-of-technology-appraisal-guidance-ta278

NICE Interventional Procedural Guidance: IPG419 Bronchial thermoplasty for severe asthma.
http://publications.nice.org.uk/bronchial-thermoplasty-for-severe-asthma-ipg419

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)

Quality Dimension

Effective

All people with ‘difficult asthma’ referred to a secondary level asthma service should have access to appropriate multidisciplinary assessment, if required. All people, having been assessed as above, and found to have severe persistent asthma, should be referred to tertiary services for multidisciplinary assessment and appropriate drugs therapy, if required.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people assessed to benefit from appropriate monoclonal antibody therapy who are offered a therapeutic trial.	Regional difficult asthma database	100%	March 17

6.4 ASTHMA IN CHILDREN AND YOUNG PEOPLE

Asthma is a very common condition which affects about one in 10 children.

Children and young people with asthma have airways (bronchi, or breathing tubes) which are ‘twitchy’ and are very easily made to narrow when exposed to specific stimuli. Specific triggers include breathing allergens which are in the air, such as house dust mite, grass and tree pollens; and also respiratory viral infections (e.g. ‘the simple head cold’). Triggers are many and varied, and differ from person to person. When exposed to a trigger the airways become swollen and inflamed causing ‘obstruction’ and making it hard to breathe. In addition, the airway inflammation and excessive mucous production cause increased coughing.

The symptoms of asthma include wheezing (a whistling noise made when breathing out through narrowed airways), shortness of breath and coughing. The symptoms typically come and go.

During an asthma attack the inflammation and swelling causes the airways to become very narrow and children become very breathless and such attacks can be life threatening.

Recently it has been observed that while the inflammation becomes less intense in between asthma attacks it is never fully switched off. It is thought that this ongoing, low grade inflammation may account for why many children experience symptoms in between attacks, such as when they exercise in cold air, at night, or if exposed to a smoky environment.

The airways narrowing, which causes great difficulty in breathing air out of the lungs, can be measured and monitored in children older than about 5 years using lung function equipment called a spirometer. The narrowing can be measured as the largest volume that a child can blow out in one second (Forced Expiratory Volume in 1 second, FEV1).

Many children with asthma have also an allergic tendency and may also suffer from hay fever (allergic rhinitis) and eczema.

There is no cure for asthma. The aim of treatment is to reduce the frequency and severity of asthma symptoms. Therefore it is important that children and young people and their families know how to manage asthma.

There are three aspects of treatment:

1] Primary prevention

There is evidence that smoking when pregnant is related to the onset of asthma in children (Standard 5.2) so it is important that women are given this information and advice about smoking cessation at antenatal clinics.

2) Prevention and control of chronic asthma

It is impossible to prevent children getting asthma attacks which are triggered by viral head colds.

Exposure to environmental tobacco smoke (passive smoking) can make asthma worse and families should be advised about this.

Some children have allergies which are significant triggers of their asthma and continuing exposures to these allergens may continuously provoke airway inflammation. A detailed allergy history is important to identify specific triggers that might be removed.

Children with asthma should have a ‘reliever’ (usually a blue inhaler) which contains medicine that helps to open up the airways. Reliever inhalers are used ‘when required’. Those with more chronic asthma with day-to-day symptoms or frequent asthma attacks are prescribed ‘preventer’ therapy (usually an inhaled steroid) which needs to be taken regularly and aims to damp down the inflammatory response.

It is important that the child/family is offered education and on-going support to understand:

- what triggers the asthma and if possible how to avoid the triggers
- how to assess the severity of an attack and have a written action plan
- understand the roles of their preventer and reliever medication, when to use each, and how to use the medication devices

3) Management of acute attacks

The child/family need to know how to identify and manage an acute attack of asthma and when to seek further help. For more severe attacks, which cannot be managed at home, the family needs to know where to get help rapidly (services or hospital emergency departments). The GP out of hours services and hospital emergency departments (ED) need to be able to accurately assess severity and provide appropriate urgent treatment for acute asthma. It is very important that children who have attended GP out of hours services have a review of their asthma control soon afterwards.

Anaphylaxis

If a child has experienced an anaphylactic reaction with very rapid onset of severe wheezing (which can be fatal) and cardiovascular collapse, there should be an urgent assessment and treatment by a suitably trained team. It is important that an attempt is made to identify the offending food allergen so that it is avoided in the future and that the child/family are instructed in what to do if the child is accidentally re-exposed to the offending trigger.

Overarching Standard 25 – Diagnosis of asthma
All children and young people with suspected asthma should have assessment and investigations to confirm the diagnosis.

Rationale:
Asthma in childhood, especially those < 5 years, can be difficult to diagnose. It can be difficult to know if parental reported wheeze is true wheezing and whether children and young people with recurrent cough have asthma. Objective measures are therefore required to establish an accurate diagnosis. If a 'trial of asthma medication' is used to confirm the diagnosis in younger children a clear record of the outcome should be recorded.

Allergic rhinitis affects 10-25% of the population and has a direct relationship with asthma. Good rhinitis control contributes positively to asthma control.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Allergic Rhinitis and its Impact on Asthma (ARIA) guidelines: 2010 revision. Brożek, Jan L., et al. *Journal of Allergy and Clinical Immunology* 126.3 (2010): 466-476.
http://www.jacionline.org/article/S0091-6749(10)01057-2/abstract

Responsibility for delivery / implementation

HSC Board
Public Health Agency (PHA)
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions			
Safe - All staff performing and interpreting spirometry should have undergone appropriate training. - In primary care, relevant practice staff must be appropriately trained to meet modern authoritative standards. Training needs of staff should be reviewed regularly in line with recommendations from HSCB. **Effective** - All children and young people with a diagnosis of asthma, where possible, should have a documented record of an objective test to confirm the diagnosis (which may be a 'therapeutic trial' with a documented outcome) and demonstrate variability in airways obstruction (spirometry, outcome) PEFR diary card variability can be useful supportive evidence of an asthma diagnosis, but is not useful for subsequent asthma management and, as it is a measure of very large airway calibre, can be normal in children and young people with reduced FEV1.			
Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people aged 8 or over with asthma (diagnosed on or after 1 April 2006) on the register with measures of variability or reversibility recorded between 3 months before or any time after diagnosis. (QOF AST indicator 002)	QOF	80%	March 16

Overarching standard 26 – Self-management
All children and young people with asthma and their parents/guardians should be given the opportunity to learn about their condition and receive a written individualised self-management action plan.

Rationale:
There is high quality clinical trial evidence supporting the use of personalised action plans in the self-management of asthma to improve asthma outcomes, including patient self-efficacy and confidence as well as reduce hospital admission rates. The evidence for written, personalised action plans is strongest when given as part of a structured education programme and combined with regular practitioner review.

There is evidence to show that children and young people with asthma have their condition exacerbated by the effects of passive smoking.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Written action plans for asthma in children. Bhogal SK, Zemek RL, Ducharme F. Cochrane Database of Systematic Reviews 2006, Issue 3.
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD005306.pub2/abstract

Educational interventions for asthma in children. Wolf F, Guevara JP, Grum CM, Clark NM, Cates CJ. Cochrane Database of Systematic Reviews 2002, Issue 4.
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000326/abstract

Interventions for educating children who are at risk of asthma-related emergency department attendance. Boyd M, Lasserson TJ, McKean MC, Gibson PG, Ducharme FM, Haby M. Cochrane Database of Systematic Reviews 2009, Issue 2.
http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD001290.pub2/abstract

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions

Safe

- Children and young people should be seen within 1 month after an initial visit confirming an asthma diagnosis and if stable 6-12 monthly thereafter in primary care. The frequency and location of subsequent reviews does depend however on severity, e.g. if a child has been admitted to PICU, they should be reviewed by secondary care within a shorter timescale.
- Children and young people with asthma who also have an allergy need to be aware that they may deteriorate more rapidly than children and young people without an allergy.

Effective

- Children and young people and their families should be offered the opportunity to jointly agree, with the health care professional, an asthma self-management plan and be taught to:
  - identify and avoid risk factors
  - take medications correctly
  - understand the difference between preventer and reliever inhalers
  - recognise signs that their asthma is worsening
  - know when and how to take action.
- All children and young people with asthma who smoke should have their smoking status recorded, be offered appropriate smoking cessation advice and access to specialist smoking cessation services. The parents/carers of children and young people with asthma should be advised of the effects of passive smoking on the condition.
- Each child should be taught and should demonstrate that they can use an age-appropriate inhaler device effectively.

Person Centred

- All people with asthma should be given the opportunity to learn about all aspects of the disease process to include the nature of the disease, rationale for symptoms experienced, description of treatments and their function, treatment options, and help with the identification and avoidance of risk/trigger factors.
- Where appropriate, families / carers should be involved, especially for

children or where the young person with asthma may have reduced capacity for example, learning disability.

- Schools should be supported by the specialist asthma and allergy service and the school nursing service to develop and implement policies and training for asthma.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of children and young people with asthma step 2 and above who have had individualised face to face information and written self-management action planning.	Regional LES	80%	March 16
Percentage of children and young people (under 14) with a diagnosis of asthma that attended and have been asked to demonstrate their inhaler technique at asthma review.	Regional LES	80%	March 16
Percentage of schools supported with policies and training for asthma.	HSC Trust Report	Baseline to be established Performance levels to be determined	March 16
Percentage of young people with asthma aged 14 or over and who have not attained the age of 20, on the register, in whom there is a record of smoking status in the preceding 15 months.	QOF	80%	March 16

Overarching standard 27 – Management of acute severe asthma
All children and young people with acute severe asthma should be accurately assessed and managed appropriately according to the severity of their presentation.

Rationale:
Acute severe asthma can be a life threatening condition. Confidential enquiries into asthma deaths have identified poor recognition, or assessment of deterioration, by both patients and health care providers as a potential contributory factor, emphasising the importance of prompt and accurate assessment of this condition.

The current NICE quality standards for asthma recommend that people with asthma who present with an exacerbation of their symptoms receive an objective measurement of severity at the time of presentation. A Northern Ireland audit of management has highlighted areas for improvement in the management of acute exacerbations.

If a child or young person requires emergency management for an acute exacerbation of asthma, it is important that they are reviewed soon afterwards to consider their on-going management to ensure they are receiving optimal therapy.

Evidence:
British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Out-of-hours providers
Integrated Care Partnerships (ICPs)

Quality Dimensions

Safe

- Safe timely transfer (supervised by suitably trained staff) should be available to PICU for those with life threatening asthma.

Effective

- Children and young people with severe or life threatening asthma should have an agreed plan for rapid access to emergency care.
- An assessment of severity (as per BTS guidelines) should be made and documented along with documentation of the response to treatment.
- Each child should receive evidence based management during acute exacerbations and followed up in primary care in line with current best practice guidelines.
- On discharge children's management plans should be reviewed to try and prevent readmission. Children and young people discharged from hospital (admission or ED) or from out-of-hours services should be reviewed within 14 days.
- Asthma specialist paediatric nurses should liaise with GPs and practice nurses to ensure coordinated care for children who attend ED, ambulatory care or are admitted.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of children / young people presenting with acute severe asthma to ED or OoH* who have an oxygen saturation 94% or less, who have a post bronchodilator oxygen saturation carried out and result recorded (if remains less than 92%, person should be admitted). **only those people requiring to be nebulised in OoH*	OoH audit	60% 80%	March 16 March 17
	ED audit care bundle methodology every 6 months	60% 80%	March 16 March 17
Percentage of GP practices with a red flag system to identify children / young people presenting with acute severe asthma within the previous 12 months in GP practices, OoH, emergency departments or ambulatory care settings.	Regional LES to be agreed	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of children / young people with acute severe asthma presenting in GP practices, OoH, emergency departments or ambulatory care settings with a record of follow-up (telephone or face-to-face) within 14 days of the episode by the GP, practice nurse, community or secondary care.	Regional LES to be agreed	Baseline to be established Performance levels to be determined	March 17 March 18

Percentage of children and young people with acute severe asthma who attend emergency departments, ambulatory departments or are admitted, who are reviewed (by telephone or face-to-face) by an asthma specialist paediatric nurse within 14 days.	Trust report	Baseline to be established Performance levels to be determined	March 16 March 17

Overarching standard 28 – Management of acute anaphylaxis

No child or young person should have a second unmanaged anaphylactic event.

Rationale:

Deaths from acute anaphylaxis in young people are most often triggered by food. Significant cofactors in these deaths can be asthma co-morbidity, lack of timely epinephrine and non-attendance at specialist allergy outpatient clinics.

A detailed history from an appropriately trained specialist is important to confirm the trigger event. Education including dietetic support, avoidance measures and instruction in use of adrenalin auto injector devices is important. Psychological support may be needed to support management of the effects of anxiety and quality of life and adherence to management guidelines. All children attending schools should have an action plan for anaphylaxis.

Evidence:

NICE Clinical Guideline 134 Anaphylaxis: assessment to confirm an anaphylactic episode and the decision to refer after emergency treatment for a suspected anaphylactic episode http://www.nice.org.uk/cg134

NICE Clinical Guideline 116 Food allergy in children and young people: Diagnosis and assessment of food allergy in children and young people in primary care and community settings http://www.nice.org.uk/cg116

Royal College of Paediatrics and Child Health Allergy Care Pathways for Children: Anaphylaxis (2011)
http://www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/anaphylaxis/care-pathway-anaphylaxis

Royal College of Paediatrics and Child Health Allergy Care Pathways for Children: Food Allergy (2011)
http://www.rcpch.ac.uk/child-health/research-projects/care-pathways-children-allergies/food-allergy/care-pathway-food-aller

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Integrated Care Partnerships (ICPs)

Quality Dimension

Effective

- All children and young people with acute anaphylaxis should be assessed and investigated by a suitably trained team within 2 weeks of the episode. The team should include a paediatrician with an interest in asthma/allergy, a dietician with an interest, and an asthma/allergy specialist nurse.
- Accurate diagnosis and assessment should minimise the number of people who have adrenalin auto-injector devices prescribed.
- Accurate diagnosis and assessment should minimise the inappropriate restriction of a child's diet.

Efficient

- Schools should be provided with annual updates on the recognition and treatment of acute anaphylaxis by the specialist asthma and anaphylaxis service and the school nursing service.

Safe

- Children with asthma and who are at risk of anaphylaxis should have one multidisciplinary team responsible for both their conditions.

Person Centred

- All children and young people at risk of anaphylaxis should receive an educational package to empower them and/or their family to know what triggers to avoid, how to recognise an allergic reaction and how to give emergency treatment if required.
- Children and young people who have an anaphylactic reaction may benefit from psychological support to manage anxiety and the effects on quality of life and management of treatment.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of children younger than 16 years who have had emergency treatment for suspected anaphylaxis who are admitted to hospital under the care of a paediatric medical team.	HSC Trust audit	100%	March 16

Percentage of children / young people who are referred to a specialist allergy service within 2 weeks of the primary episode (age-appropriate where possible) after emergency treatment for suspected anaphylaxis.	HSC Trust audit	100%	March 16
Percentage of children / young people who are routinely prescribed an adrenalin auto-injector device who have not had the diagnosis confirmed at a specialist allergy service.	GP audit	Baseline to be established Performance levels to be determined	March 16 March 17
Percentage of schools attending an annual update on the recognition and treatment of acute anaphylaxis.	HSC Trust report	Baseline to be established Performance levels to be determined	March 16 March 17
Percentage of specialist staff within the asthma and allergy service that have had training in the management of emotional, social and psychological issues of children and young people with severe generalised allergic and anaphylactic reaction.	HSC Trust report	50% 90%	March 16 March 17
Percentage of Trusts who have developed pathways for emotional, social and psychological support for children with severe generalised allergic reactions and anaphylaxis, as set out in the emotional, social and psychological support section of this service framework.	HSC Trust report	All trusts	March 17

Overarching standard 29 – Management of difficult asthma at secondary and tertiary level

All children / young people with ‘difficult asthma’* should be assessed and managed by a team with the appropriate skills and experience.

*’Difficult asthma’ is defined as those who are symptomatic on BTS/SIGN guidelines step 4 treatment and all people on step 5 treatment.

Rationale:

On-going monitoring is essential to maintain control and establish the lowest step and dose of treatment. Proactive intervention can prevent acute exacerbations of asthma and reduce an individual’s need for medication and hospital admission.

The BTS/SIGN guidelines recommend that children and young people above a certain level of treatment, or where there is a diagnostic uncertainty, should be referred to secondary care.

A small number of children and young people have more difficult and severe asthma and require high doses of inhaled and oral steroids. In these circumstances, secondary care needs to have access to specialist tertiary care services which will also have an important role in assessing for the provision of new therapies.

Steroid alert cards should be given to children and young people who are on beclometasone dipropionate or budesonide 800 mg/day (or fluticasone propionate 400 mcg/day)

Evidence:

British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a ‘Living Guideline’ i.e. is updated annually]
http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

NICE quality standard for asthma, QS25
http://publications.nice.org.uk/quality-standard-for-asthma-qs25

NICE interventional procedure guidance (IPG419) Bronchial thermoplasty for severe asthma
http://publications.nice.org.uk/bronchial-thermoplasty-for-severe-asthma-ipg419

NICE technology appraisal 278 (TA278) Omalizumab for treating severe persistent allergic asthma (review of technology appraisal guidance 133 and 201)
http://publications.nice.org.uk/omalizumab-for-treating-severe-persistent-allergic-asthma-review-of-technology-appraisal-guidance-ta278

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions

Safe

- A steroid alert card should be given to children and young people who are on beclometasone dipropionate or budesonide 800 mg/day (or fluticasone propionate 400 mcg/day) or more.

Effective

- Improved asthma control can reduce unscheduled asthma admissions.
- There should be clear criteria for referral from primary to secondary care to tertiary care.
- There should be clear guidance when a child with asthma can be discharged back to primary care for ongoing management of asthma by the GP /asthma nurse.
- A multidisciplinary tertiary specialist service should be able to respond to referrals in a timely fashion (within 4-6 weeks).

Person Centred

- Children and young people who have evidence based care have greatly improved quality of life and educational attainment.
- Children and young people with difficult to treat asthma that does not respond to treatment should have home visits to identify modifiable risk factors and support them and their families to make appropriate changes.
- Children and young people with difficult and severe asthma can need psychological support to manage the effects on quality of life and management of treatment.

Performance Indicator:	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of children and young people on beclometasone dipropionate or budesonide 800 mg/day (or fluticasone propionate 400 mcg/day) who have been given a steroid alert card.	Outpatient audit (via Paeds Respiratory & Allergy network)	90%	March 16
Percentage of children and young people attending outpatients who have had appropriate management as per BTS guidelines.	Outpatient audit (via Paeds Respiratory & Allergy network)	90% for each criterion	March 16
Percentage of children and young people who are admitted, who have appropriate inpatient and discharge planning as per BTS guidelines.	BTS Paediatric Asthma audit (via Paeds Respiratory & Allergy network)	40% 60% 80% for each criterion	March 16 March 17 March 18
Percentage of children and young people with difficult to treat asthma who do not respond to treatment attending a secondary care service, who have a home visit from a specialist respiratory nurse.	HSC Trust report	40% 60% 80%	March 16 March 17 March 18
Percentage of children and young people with difficult to treat asthma who do not respond to treatment attending the tertiary service, who have a home visit from a specialist respiratory nurse.	RBHSC Tertiary care service report	40% 60% 80%	March 16 March 17 March 18

Percentage of specialist staff within the asthma and allergy service that have had training in the management of emotional, social and psychological issues of children and young people with difficult asthma.	Trust report and RBHSC tertiary care service report	50% 90%	March 16 March 17
Percentage of Trusts who have developed pathways for emotional, social and psychological support for children with difficult asthma, as set out in the emotional, social and psychological support section of this service framework.	HSC Trust report and RBHSC tertiary care service report	All Trusts	March 17

6.5 COMMUNITY ACQUIRED PNEUMONIA IN ADULTS

Community acquired pneumonia (CAP) refers to an infection in the lungs that is picked up outside of the hospital setting. It is estimated that about 14,000 people are treated for CAP in Northern Ireland each year and it is one of the main reasons for admission to hospital with a chest problem. Most people with CAP make a full recovery with the correct treatment, but CAP can be a very serious illness.

CAP is caused when harmful germs get past the defence systems of the lungs and start to multiply, causing an infection. These germs may already be present in the person's nose or throat, or may be breathed in from droplets in the air (for example after someone sneezes). The infection can affect both lungs or only one.

People are more at risk of getting CAP if they are elderly, smoke, or drink too much alcohol. Other serious illnesses can increase the risk of getting CAP too, by weakening the body and its natural defences against infection.

It is important that people who have severe enough illness to require hospital admission receive treatment according to the highest standards available, as this reduces the risk of death and complications from CAP.

Overarching standard 30 – All people with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to BTS pneumonia guidelines.

Rationale:

Appropriate assessment, diagnosis and management in line with evidence based guidelines leads to a reduction in morbidity and mortality. Appropriate antibiotic usage based on local prescribing guidance contributes to reducing the risk of health care associated infections.

The BTS guidelines provide a general recommendation for the diagnosis and management of adults of all ages with suspected CAP. They do not aim to cover management of CAP for individuals with known predisposing conditions such as cancer or immunosuppression admitted with pneumonia to specialist units such as oncology, haematology, palliative care or infectious diseases units, where specialist input is warranted.

Evidence:

British Thoracic Society (BTS) Guidelines for the Management of Community Acquired Pneumonia in Adults (2009 update).
http://www.brit-thoracic.org.uk/guidelines-and-quality-standards/community-acquired-pneumonia-in-adults-guideline/

NHS Antimicrobial prescribing: A summary of best practice
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=147766&Rendition=Web.

Strategy for Tackling Antimicrobial Resistance (STAR) 2012 – 2017. DHSSPSNI (June 2012)
http://www.dhsspsni.gov.uk/health_protection-antimicrobial_resisitance

Northern Ireland Antimicrobial Guidelines for Secondary Care (local guidance available for each HSC trust)

Responsibility for delivery / implementation

HSCB
Public Health Agency (PHA)
Lead HCAI director for each trust
HSC Trusts

Quality Dimensions

Safe

- Antibiotic therapy for people with CAP should be in line with trust guidance to reduce the risk of health care associated infections.

Timeleness

- People with CAP who have a CURB-65 score of 3 or more should be urgently admitted to hospital with senior review at the earliest opportunity.
- All people with CAP should receive antibiotics as soon as the diagnosis is confirmed. People with life threatening disease may be treated based on a presumptive clinical diagnosis.

Effective

- Assessment, diagnosis and management should be in line with BTS guidelines. A diagnosis of CAP should be confirmed by chest radiograph before the commencement of antibiotics in the majority of people. Selected people with life-threatening disease should be treated based on a presumptive clinical diagnosis of CAP, with an urgent chest radiograph as soon as possible to confirm the diagnosis or to indicate an alternative diagnosis.
- All people admitted to hospital with CAP should have regular assessment of disease severity. For those deemed at high risk of death on admission, it is recommended that medical review should occur at least 12 hourly to reassess severity and monitor response to treatment. Individuals with CURB-65 scores of 4 and 5 should be assessed with specific consideration to the need for transfer to a critical care unit (high dependency unit or intensive care unit) where appropriate.

Person Centred

- The person’s individual circumstances and wishes must be taken into account in all instances when deciding where and how they should be managed.

Performance Indicator	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of people admitted to hospital with suspected CAP who have a chest x-ray performed and reviewed before being commenced on antibiotic therapy for CAP.	BTS CAP audit	80% 90%	March 16 March 18
Percentage of people with CAP in whom diagnosis is confirmed by chest radiograph and first antibiotic dose administered within 4 hours from admission*.	BTS CAP audit	80% 90%	March 16 March 18
Percentage of people diagnosed with CAP who receive antibiotics in line with trust guidance. *(appropriateness should be verified by antimicrobial pharmacist and microbiologist)*	BTS CAP audit	80% 90%	March 16 March 18
Percentage of people diagnosed with CAP who are reviewed by a consultant within 24 hours of admission*. **time of admission refers to the presentation time at the hospital (ambulance transfer sheet/time recorded in notes) if this is available.*	BTS CAP audit	90% 95%	March 16 March 18

6.6 COMMUNITY ACQUIRED PNEUMONIA IN CHILDREN AND YOUNG PEOPLE

Acute pneumonia is infection and inflammation in the small air sacs and tissues of the lung, rather than infection/inflammation in the breathing tubes (bronchi) which is called 'bronchitis.' Community acquired pneumonia is infection picked up outside of hospital.

It is estimated that around 8,000 children under the age of 14 are likely to develop community acquired pneumonia each year. This condition is twice as common in children aged under five as in older children.

Children with pneumonia develop a temperature, cough, grunty breathing and increased breathing effort (fast breathing and indrawing of tummy muscles). Although viral infections are the most common cause of pneumonia and do not require antibiotics, about a third of cases are due to potentially serious bacterial infections and thus appropriate antibiotics are required.

The majority of children with pneumonia can be managed in primary care but, for some, assessment and/or admission to hospital will be required.

Very occasionally the pneumonia will become complicated – for example when fluid and pus leak out and accumulate between the outer surface of the lung and the inner surface of the chest wall (ribs). Infected fluid and pus in this space between the lungs and the rib cage (pleural space) typically contuse to expand causing compression on the lung. This complication is called "empyema" and these children become very unwell with uncontrolled infection and reduced ability to maintain adequate breathing. They require referral to the Royal Belfast Hospital for Sick Children (RBHSC) where the empyema is surgically drained, and powerful antibiotics are used. Some children may require intensive care treatment.

Children who have suffered recurrent episodes of pneumonia will require to be referred to a paediatrician to determine if there is any underlying reason for the repeated pneumonias, such as an immune deficiency.

Overarching Standard 31 – Assessment, diagnosis and treatment

All children and young people with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to the BTS Guidelines.

Rationale:

The early assessment and diagnosis of pneumonia allows a clinically appropriate management plan to be implemented with effective and efficient use of resources and appropriate antibiotics and, where necessary, admission to hospital. This can lead to a reduction in morbidity and mortality and reduce unnecessary cost pressures.

Children with more complex disease are likely to require the experience of clinicians who manage this condition regularly. These children may also require imaging or procedures only available in a tertiary centre.

Evidence:

British Thoracic Society (BTS) Guidelines for the management of community acquired pneumonia in childhood (2011) http://www.brit-thoracic.org.uk/guidelines/pneumonia-guidelines.aspx

British Thoracic Society (BTS) Guidelines for the management of pleural infection in children (2005, reviewed 2008) http://www.brit-thoracic.org.uk/Guidelines/Pleural-Infection-in-Children-Guideline.aspx

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care
Out of Hours Services
Regional Transport Team

Quality Dimensions
Effective - Children and young people should be diagnosed and managed according to the BTS guidelines. - Children with complex pneumonia who are not responding to treatment should be managed in a tertiary centre. - Children and young people with infected pleural effusions and empyemas should be referred to the tertiary respiratory unit as per “BTS guidelines for pleural infection in children”. **Safe** - Children with respiratory failure requiring transport from a secondary to tertiary level care facility should be appropriately assessed and transferred safely. Transfers should not delay starting appropriate treatment where possible. **Person centred** - Children and young people should be managed in the most appropriate setting and inappropriate admissions avoided to minimise adverse impact on them and their families.

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of children and young adults diagnosed with CAP who are appropriately investigated and managed as per BTS guidelines in the following key areas: • Chest x-ray (assessment and post discharge) • Routine blood tests • Antibiotic therapy • Oral versus IV antibiotics • Post-discharge follow-up in secondary care	A&E records Assessment centre records Hospital In-patient data Care bundle audit repeated 6-monthly	75% 90%	March 2016 and 6-monthly thereafter March 18
The percentage of children with CAP transferred from another hospital to a ward in RBHSC who are admitted to PICU within 24 hours of arrival in RBHSC.	Audit of ICU records & telephone records	20% 10%	March 16 March 17
Percentage of children and young people requiring admission to PICU with CAP who are admitted within 6 hours of decision to admit.	Audit of ICU records & telephone records	80% 90%	March 16 March 17

6.7 OBSTRUCTIVE SLEEP APNOEA/HYPOPNOEA SYNDROME (OSAHS) IN ADULTS

What is Obstructive Sleep Apnoea Hypopnoea Syndrome (OSAHS)?

Obstructive Sleep Apnoea Hypopnoea Syndrome is a condition where breathing reduces or stops during sleep due to obstruction in the upper airway, causing excessive sleepiness during the day. This obstruction is most commonly caused by relaxation of the muscles in the upper airway. In healthy individuals, some relaxation of muscle tone in the upper airway occurs normally during sleep. However, it is more pronounced in people who have OSAHS.

During deep sleep, muscle relaxation is at its peak, and results in a temporary obstruction of the upper airway in people with OSAHS. Airflow to the lungs is then interrupted by this temporary obstruction.

If there is a partial obstruction, airflow to the lungs is decreased and this is called a hypopnoea. If there is complete obstruction of the airway, airflow to the lungs stops and this is called an apnoea, a Greek work meaning ‘without breath’.

When airflow to the lungs is decreased or stops, oxygen levels in the blood may decrease. This reduction in blood oxygen levels then alerts the brain to the problem. The brain then needs to arouse the person from deep, relaxed sleep to restore muscle tone. The upper airway then opens and breathing begins again. Often the person is not aware of being woken up but their sleep has been interrupted. Unfortunately when a person with OSAHS falls back into deep sleep, the muscles relax once more and the cycle repeats itself, again and again, throughout the night.

In OSAHS, the apnoeas can last for several seconds and in severe cases the cycle of apnoeas and broken sleep is repeated hundreds of times per night. Most sufferers are unaware of their disrupted sleep, but awaken unrefreshed, feeling sleepy and in need of further sleep.

People with OSAHS experience excessive daytime sleepiness as a result of their disturbed sleep. They may also experience poor concentration, decreased work performance, marital problems, reduced quality of life and decreased driving safety due to their daytime sleepiness.

Who gets OSAHS?

OSAHS is most common in overweight, middle aged males who snore. It affects up to 4% of middle aged males and up to 2% of middle aged females. It is estimated that between 11,000 and 22,000 people in Northern Ireland, aged 30-64, have OSAHS (Regional OSAHS Strategy for adults in Northern Ireland, 2007). Obesity is a significant risk factor for OSAHS as increased neck circumference increases the likelihood of airway obstruction.

However, OSAHS may also occur in people who are not obese. In such people, a small jaw, enlarged tongue, large tonsils and long soft palate help to block the upper airway in deep sleep, making OSAHS more likely to occur. The use of alcohol, sleeping tablets and tranquillisers prior to sleep relaxes the upper airway muscles and make OSAHS worse. Alcohol can also reduce the brain's response to an apnoea which in turn leads to longer and more severe apnoeas.

What are the symptoms of OSAHS?

Most common symptoms of OSAHS include:

Daytime

- Excessive daytime sleepiness (most commonly reported by men)
- Fatigue (most commonly reported by women)
- Feeling unrefreshed in the morning despite an adequate period in bed
- Morning headaches
- Poor concentration and poor memory
- Decreased work performance and productivity
- Irritability
- Low mood
- Personality change
- Loss of libido
- Impotence
- Feeling drowsy while driving

Night-time

- Apnoeas witnessed by a bed partner (pauses in breathing are often followed by loud gasping and loud snoring)
- Loud snoring
- Waking from sleep due to gasping/shortness of breath
- Multiple awakenings during the night due to unknown cause
- Fragmented/restless sleep

- Night time sweating
- Passing urine at night

What are the consequences of untreated OSAHS?

Excessive daytime sleepiness significantly impairs quality of life. Work performance can be affected with serious consequences for the individual including accidents and falling asleep at work.

Individuals with uncontrolled OSAHS have an increased rate of road traffic accidents (RTAs), varying between 3 and 7 times that of the general population (IMPRESS guidelines 2009). Accidents not only occur due to falling asleep at the wheel but also from impaired concentration due to sleepiness.

Untreated OSAHS is an independent risk factor for high blood pressure and therefore, may be contributory to other cardiovascular diseases such as angina, heart attack and stroke. It may also be contributory to Type 2 diabetes and poor blood sugar control.

Because OSAHS significantly increases the risk of road traffic accidents, people must not drive if experiencing excessive daytime sleepiness. Individuals must inform the Driving Vehicle Agency (DVA) in Northern Ireland following a diagnosis of the condition. In most cases, the DVA allows car drivers to continue driving once they are established on a successful therapy and no longer experience daytime sleepiness.

How is OSAHS assessed?

If OSAHS is suspected, the person experiencing symptoms should attend their GP for initial assessment. The doctor will take a ‘history’ that includes questions about waking and sleeping habits and perform a physical examination, which may involve looking inside the mouth. The person may be asked to complete a questionnaire about their level of daytime sleepiness called the Epworth Sleepiness Scale.

Reports from a bed partner or household member about any apnoeas and sleep quality can be very useful, as it is often a loved one who notices the night-time symptoms. The person will then be referred to their local sleep service within their local Trust for an overnight sleep study called overnight oximetry. This measures any dips in the blood oxygen levels overnight. This sleep study will be performed in the home after appropriate instruction from the sleep diagnostic unit. This sleep study is required to confirm the presence of OSAHS and help determine its severity.

In some instances, the initial sleep study may be inconclusive and a further sleep study called limited polysomnography (PSG) or limited respiratory sleep study may be required to confirm the diagnosis. This measures airflow and chest wall movement as well as blood oxygen levels.

In the majority of cases, either an overnight oximetry test or a limited respiratory sleep study are sufficient in making the diagnosis of OSAHS, alongside results from physical examination and a clinical history and should be available in the person’s local trust area.

In more complex cases, a full polysomnography (PSG) test may be required and a referral to a regional sleep centre will be required. Full PSG measures the person’s sleep quality as well as leg movements during sleep in addition to chest wall movement, airflow and blood oxygen levels. It can give more information on complex sleep apnoea and also investigate other sleep disorders that may be present. None of the sleep studies are painful or difficult to take part in.

How is Obstructive Sleep Apnoea Hypopnoea Syndrome treated?

Every person diagnosed with OSAHS, whether it is mild, moderate or severe should alter lifestyle factors such as losing weight, reducing alcohol intake (especially before bedtime), stop smoking and avoid sleeping tablets. Good sleep hygiene is also very important, such as a regular bedtime and getting up time, having a cool, dark, quiet room to sleep in with no distractions such as television, radio or computers and drinking less caffeine e.g. tea, coffee, cola drinks.

For people diagnosed with moderate/severe OSAHS, treatment with continuous positive airway pressure (CPAP) is recommended by NICE guidelines. CPAP involves wearing a mask during sleep that provides a flow of normal air which holds the airway open during sleep and prevents the obstruction at the back of the throat that causes OSAHS.

Another form of treatment is an intra-oral device that attempts to keep the airway clear by moving the jaw forward. This device may be effective for some people with mild OSAHS, but is not appropriate for all, in particular, those diagnosed with moderate/severe OSAHS. However, it may be considered in people who are unable to tolerate CPAP.

Overarching standard 32
All adults with a clinical suspicion of having obstructive sleep apnoea / hypopnoea syndrome (OSAHS), should have investigation (ie. overnight oximetry and/or limited polysomnography) at a specialist OSAHS service in their local Health and Social Care Trust led by a respiratory physician.

Rationale:
Any individual with symptoms suggestive of OSAHS should have timely investigation and treatment by appropriately trained staff. OSAHS is a treatable condition but untreated, causes severe sleepiness. Untreated OSAHS may also have cardiovascular consequences and affect driving safety.

Evidence:
National Institute for Health and Clinical Excellence (NICE) (2008) Continuous positive airway pressure for the treatment of obstructive sleep apnoea / hypopnoea syndrome http://guidance.nice.org.uk/TA139

Scottish Intercollegiate Guidelines Network (SIGN) (2003) Management of Obstructive Sleep Apnoea /Hypopnoea in Adults http://www.sign.ac.uk/pdf/sign73.pdf

Regional Obstructive Sleep Apnoea Hypopnoea Strategy for Adults in Northern Ireland (October 2007)

American Academy of Sleep Medicine, Kushida et al, Practice parameters for the indications for polysomnography and related procedures: An update for 2005. Sleep 2005, 28 (4): 499-521

American Academy of Sleep Medicine: 'Clinical guidelines for the evaluation, management and long term care of Obstructive Sleep Apnoea in adults'. Journal of Clinical Sleep Medicine, vol 5, no.3, 2009

'Canadian Thoracic Society 2011 guideline update: Diagnosis and treatment of sleep disordered breathing' Can Respir J v.18(1);Jan-Feb 2011

IMPRESS: Service Specification for Investigation and Treatment of Obstructive Sleep Apnoea Syndrome. March 2009

ARTP Standards of Care for Sleep Apnoea Services (Diagnostics) July 2010

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary care

Quality Dimensions

Safe

- Sleep studies (i.e. overnight oximetry and limited polysomnography) are safe, non invasive and evidence based investigations for diagnosing OSAHS.
- All sleep studies should be subject to detailed manual review.
- People with suspected severe OSASH, and those working in safety-critical occupations should be investigated within four weeks of the referral to a diagnostic sleep facility.
- All staff interpreting oximetry and limited sleep studies should be appropriately trained and aware of the limitations of the tests.

Accessible

- All people who meet the SIGN guidance definition for urgent referral should be seen within 2 weeks.

Effective

- Sleep studies are effective in investigating OSAHS (SIGN guidelines). However, these tests also have limitations requiring further investigations such as full polysomnography.
- All people referred from primary care should be assessed according to the agreed protocol in the Northern Ireland Strategy.
- All people should be investigated according to the standards laid out in the Regional OSAHS Strategy.

Efficient

- All people should be referred from primary or secondary care through an efficient referral pathway with sufficient patient information to allow appropriate and timely clinical review and investigation.

Equitable

- People should be able to access the service in the local trust area.

Person Centred

- Ensure that people are investigated appropriately in their local Health and Social Care Trust in a timely manner with non-invasive tests in their home environment where possible.

Performance indicator:	Data source	Anticipated Performance Levels	Date to be achieved by
Percentage of Trusts that have specialist OSAHS services which can provide overnight oximetry; limited polysomnography and CPAP provision.	HSC Trust report	All 5 Trusts	March 17
Percentage of people with suspected severe OSAHS, or those working in safety critical occupations, who have been assessed and investigated within 6 weeks.	HSC Trust report	50% 80%	March 17 March 18
Percentage of people with lower risk OSAHS who are assessed (currently 9 weeks) and treated (currently 13 weeks) as per DHSSPS waiting time targets.	HSC Trust report	50% 80%	March 17 March 18

Overarching standard 33 – Full Polysomnography (PSG)
All people with suspected OSAHS and where a limited sleep study is negative or inconclusive in the setting of high clinical suspicion, should have timely and appropriate access to inpatient full polysomnography (PSG) in the regional respiratory centre.

Rationale:
Although most cases of OSAHS can be diagnosed by means of overnight oximetry and/ or a limited sleep study, OSAHS and sleep disorders can be missed by these techniques and therefore access to full polysomnography is essential.

Evidence:
National Institute for Health and Clinical Excellence (NICE) (2008) Continuous positive airway pressure for the treatment of obstructive sleep apnoea / hypopnoea syndrome http://guidance.nice.org.uk/TA139

Scottish Intercollegiate Guidelines Network (SIGN) (2003) Management of Obstructive Sleep Apnoea /Hypopnoea in Adults
http://www.sign.ac.uk/pdf/sign73.pdf

Regional Obstructive Sleep Apnoea Hypopnoea Strategy for Adults in Northern Ireland (October 2007)

American Academy of Sleep Medicine, Kushida et al, Practice parameters for the indications for polysomnography and related procedures: An update for 2005. Sleep 2005, 28 (4): 499-521

American Academy of Sleep Medicine: ‘Clinical guidelines for the evaluation, management and long term care of Obstructive Sleep Apnoea in adults’. Journal of Clinical Sleep Medicine, vol 5, no.3, 2009

IMPRESS: Service Specification for Investigation and Treatment of Obstructive Sleep Apnoea Syndrome. March 2009

ARTP Standards of Care for Sleep Apnoea Services (Diagnostics) July 2010

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary care

Quality Dimensions

Safe

- Full polysomnography is a safe, non invasive and evidence based investigation for diagnosing OSAHS and other sleep disorders.
- Full PSG studies should be subject to detailed manual review by an appropriately trained clinical physiologist.

Effective

- Full polysomnography is the gold standard in investigating OSAHS (SIGN guidelines, AASM).

Efficient

- People should be investigated by full PSG if limited sleep studies are not diagnostic and clinical suspicion is high, according to the standards in the Regional OSAHS Strategy.

Person Centred

- Ensure that people are investigated appropriately in a timely manner with an evidence based, non-invasive sleep study.

Performance indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Regional respiratory centre (at BCH) should establish a regional OSAHS service for people requiring full polysomnography.	Trust report	Service established	March 16
Percentage of people with normal limited sleep studies in whom OSAHS is still suspected, who have had an overnight inpatient full PSG.	Regional PSG database	60% 80%	March 17 March 18

Overarching standard 34 – Treatment - Lifestyle factors

All people with OSAHS should be provided with information on lifestyle modification and referred to services as appropriate.

Rationale:

While CPAP treatment (continuous positive airway pressure) is effective for moderate/ severe sleep apnoea syndrome, it should be prescribed in conjunction with evidence based lifestyle modifications. Obesity is the most important modifiable risk factor for the development of OSAHS. There is evidence that weight reduction can help to reduce symptoms in obese individuals with OSAHS, as well as reducing their risk of other obesity associated health problems. Alcohol consumption can also exacerbate OSAHS. It is important that lifestyle factors are assessed and that people are supported to make modifications.

Evidence:

Longer term effects of very low energy diet on obstructive sleep apnoea in cohort derived from randomised controlled trial: prospective observational follow-up study. Johansson, Kari, et al. *BMJ: British Medical Journal* 342 (2011).

Effect of a very low energy diet on moderate and severe obstructive sleep apnoea in obese men: a randomised controlled trial. Johansson, Kari, et al. *BMJ: British Medical Journal* 339 (2009).

Lifestyle intervention with weight reduction: first-line treatment in mild obstructive sleep apnea. Tuomilehto, Henri PI, et al. *American journal of respiratory and critical care medicine* 179.4 (2009): 320-327.

National Institute for Clinical Excellence (NICE, 2006) Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children http://www.nice.org.uk/cg043

Fit and Well. Changing Lives 2012 – 2022. A 10-year Public Health Strategic Framework for Northern Ireland (Consultation Document). DHSSPSNI July 2012. http://www.dhsspsni.gov.uk/fit-and-well-consultation-document.pdf

DHSSPS (2012) A 10 Year Tobacco Action Plan 2012-2022
http://www.dhsspsni.gov.uk/tobacco_strategy_-_final.pdf

DHSSPS (2012) A Fitter Future For All. Framework for preventing and addressing overweight and obesity in Northern Ireland 2012-22.
http://www.dhsspsni.gov.uk/framework-preventing-addressing-overweight-

obesity-ni-2012-22

New Strategic Direction for Alcohol & Drugs Phase 2: 2011-2016. DHSSPSNI December 2011.
http://www.dhsspsni.gov.uk/new_strategic_direction_for_alcohol_and_drugs_phase_2___2011-2016_

Scottish Intercollegiate Guidelines Network (SIGN) (2003) Management of Obstructive Sleep Apnoea /Hypopnoea in Adults
http://www.sign.ac.uk/pdf/sign73.pdf

Quality Dimensions

Effective

- All people should have access to appropriate written information on lifestyle modification as per the Regional OSAHS Strategy.
- All people with OSAHS, with a BMI of >25, should be provided with appropriate advice and services as per NICE, CREST and the Regional OSAHS Strategy.
- All people who smoke should have access to appropriate advice and services for smoking cessation as per regional strategies.
- All people should have alcohol intake assessed and given advice and/or referral as appropriate as per regional strategies.

Efficient

- All members of the MDT should have training to enable assessment and advice on lifestyle modification.

Performance indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of Trusts that have established a system to ensure that all people have the lifestyle assessment proforma completed, appropriate advice given and appropriate referral offered.	Trust report against service specification	All Trusts	March 16

Percentage of Trusts who have processes to ensure that all members of MDT (medical, nursing and respiratory physiologists) have had training in brief intervention in smoking and alcohol, and weight management and behavior modification techniques.	Trust report against service specification	80% 90%	March 16 March 17

Overarching standard 35 – Treatment CPAP
All people should have timely and equitable access to CPAP treatment, regular review and follow up at Trust level by dedicated CPAP respiratory physiologists / respiratory nurse specialists.

Rationale:
The correct use of a CPAP device is an evidence based and highly effective treatment for people with moderate/severe OSAHS (NICE). Adherence with CPAP is significantly increased with good education and adequate mask fit. For people with mild OSAHS who have symptoms that affect quality of life and activities of daily living, and lifestyle advice and other relevant treatment options have been unsuccessful or considered inappropriate, CPAP may be considered (NICE).

For those who cannot tolerate CPAP or have mild obstructive sleep apnoea with minimal symptoms, an intraoral device can be an effective alternative.

Evidence:
National Institute for Health and Clinical Excellence (NICE) (2008) Continuous positive airway pressure for the treatment of obstructive sleep apnoea / hypopnoea syndrome http://guidance.nice.org.uk/TA139

Scottish Intercollegiate Guidelines Network (SIGN) (2003) Management of Obstructive Sleep Apnoea /Hypopnoea in Adults
http://www.sign.ac.uk/pdf/sign73.pdf

Irish Sleep Society Guidelines (2010)
http://www.irishsleepsociety.org/iss_guidelines.htm

Regional Obstructive Sleep Apnoea Hypopnoea Strategy for Adults in Northern Ireland, (October 2007)

American Academy of Sleep Medicine: ‘Clinical guidelines for the evaluation, management and long term care of Obstructive Sleep Apnoea in adults’. Journal of Clinical Sleep Medicine, vol 5, no.3, 2009

IMPRESS: Service Specification for Investigation and Treatment of Obstructive Sleep Apnoea Syndrome. March 2009
ARTP Standards of Care for Sleep Apnoea Services (CPAP) April 2010

Scottish Sleep Forum: ‘Obstructive Sleep Apnoea Hypopnoea Syndrome – working towards the development of minimal standards for referral, investigation and treatment in Scotland' September 201

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Primary care

Quality Dimensions

Safe

- CPAP is a safe, non-invasive, effective and evidence based treatment for OSAHS.
- CPAP should be prescribed by a respiratory physician.
- Patient adherence to CPAP treatment should be checked on a regular basis. Annual adherence check is required by the DVA for occupational drivers.

Accessible

- Quality assured CPAP equipment and services should be available for all appropriate people in a timely fashion in their local trust, as per the NI Strategy for OSAHS.
- CPAP should be available within four weeks for people meeting urgent criteria (ie. Sleepy drivers, occupational drivers and those working in hazardous occupations).

Effective

- CPAP is an effective treatment for moderate/severe OSAHS (NICE).
- There should be availability of a wide range of interfaces (masks) to allow provision of adequate CPAP treatment. Humidifiers should be available if required.
- A sleep study should be performed 4-6 weeks post initiation of CPAP treatment to confirm adequate treatment of obstructive apnoea / hypopnoeas.
- People should have access to appropriate review arrangements for CPAP treatment (ie 4-6 wks post initiation with repeat sleep study, annual review for adherence check and replacement of consumables alongside a telephone advisory service and availability of trouble-shooting review appointments) with a dedicated CPAP nurse/physiologist in their local trust as per the NI Strategy for OSAHS.
- People who are unable to tolerate CPAP should be able to have assessment for the suitability for an intra oral device.

Efficient

- Local access to patient records (ideally held electronically) together with robust clerical and administrative support is essential for an efficient and responsive service.
- An up-to-date database should be maintained for all people on CPAP therapy and available to all staff dealing with these people. This database is also crucial for audit and service management issues.
- CPAP machines should be reclaimed if people are not using them as this will improve cost efficiency.

Person Centred

- Ensure that people are commenced on CPAP treatment in their own Health and Social Care Trust in a timely manner, receive appropriate education on their treatment and appropriate follow up and support.
- A telephone advisory service by dedicated CPAP nurses/physiologists should be available for follow up support of people using CPAP.
- Appropriate written information and advice on support organisations should be available for people.

Performance indicator	Data source	Anticipated Performance Level	Date to be achieved by
Percentage of people meeting urgent referral criteria who have commenced CPAP within 4 weeks.	CPAP database (local trusts)	95%	March 16
Percentage of people on CPAP who were treated as per the regionally agreed pathway (confirmed with sleep study 4-6wks post initiation and clinical review).	CPAP database (local trusts)	80%	March 17
Percentage of people who were reviewed on an annual basis with CPAP adherence checked.	CPAP database (local trusts)	40% 60%	March 17 March 18

6.8 OBSTRUCTIVE SLEEP APNOEA SYNDROME IN CHILDREN AND YOUNG PEOPLE

Many children and young people snore. This occurs when there is partial obstruction of the nasal passages or when the tongue ‘flops back’ against the back of the throat when a child is deeply asleep.

Obstructive sleep apnoea syndrome (OSAS) occurs when a child who snores experiences a period of complete airway obstruction. When complete obstruction occurs the child initially tries to overcome this with breathing efforts, but then completely stops breathing (apnoea). Apnoea is associated with a reduced oxygen level and an elevated carbon dioxide level in the blood, causing the child to arouse and start breathing again.

Many repeated such episodes, with arousals thoughout the night cause poor quality sleep. This in turn is associated with day time sleepiness and poor performance at school for example. In severe cases, where a child experiences long periods of low oxygen saturation at night over months and years, this can result in an irreversible strain on the heart.

There are many causes of OSAS including:

- Large tonsils and adenoids
- Obesity (becoming more common in children)
- Obesity syndromes – some children have syndromes associated with morbid obesity e.g. Prader Willi syndrome
- Craniofacial abnormalities e.g. cleft lip/palate
- Down’s Syndrome – where children have a large tongue relative to their throat size and a tendency for their tongue to flop back when asleep.

Diagnosis is made following a detailed history and specialised tests, some of which can be carried out at home. The treatment depends on the cause and can include:

- Make more space in the airway such as removing the tonsils and adenoids.
- Using a face mask at night to provide a continuous positive airways pressure (CPAP) to keep the airways from collapsing when asleep.

Overarching standard 36
All children and young people with obstructive sleep apnoea syndrome should have the condition accurately assessed for severity and treated in a timely fashion.

Rationale:
Most children and young people snore at some time but not all have OSAS. Childhood OSAS is relatively common and may cause significant morbidity. It is associated with day time sleepiness, poor school performance and behavioural disorders (e.g. ADHD). The causes differ from those in adults, with physical upper airway narrowing being common, as is seen in adenotonsillar hypertrophy and craniofacial structural abnormalities. Abnormalities of upper airway tone also contribute and OSAS is therefore very common in Down's Syndrome. Syndromes with morbid obesity (e.g. Prader Willi syndrome) and 'common obesity' are currently less common causes, but childhood obesity is on the rise.

Currently it is unclear in the literature whether overnight home monitoring with oxygen saturation and heart rate is an adequate screening test for those needing treatment, or if further more detailed polysomnography is required. The mainstay of treatment in OSAS secondary to adenotonsillar hypertrophy is adenotonsillectomy (AT). In children with OSAS who do not have adenotonsillar hypertrophy or those who have residual OSAS following AT, continuous positive airway pressure (CPAP) may be considered.

Evidence:
Principles and Practice of Pediatric Sleep Medicine. Editor SH Sheldon. Elsevier 2005. ISBN: 0-7216-9458-6
http://www.elsevier.com/wps/find/bookdescription.cws_home/699412/description#description

Marcus C, Brooks LJ, Ward SD et al. Diagnosis and management of Childhood Obstructive Sleep Apnea Syndrome. Pediatrics 2012 Sept 130 (3) e 714-55. American Academy of Pediatrics.
http://pediatrics.aappublications.org/content/130/3/e714.long

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
RBHSC

Quality Dimension

Safe

- The overarching aim is a reduction in morbidity associated with OSAS, for example cognitive impairment, pulmonary hypertension.
- All children with suspected OSAS should have access to assessment and management by an appropriately trained clinician within a paediatric setting. Assessment of severity should involve a detailed history and home screening tests (e.g. overnight oxygen saturations and heart rate) by a trained specialist who is aware of the limitations of these screening tests.
- Limited sleep studies should include, as a minimum, measures of:
    - Snoring
    - Air flow
    - Thoraco-abdominal movement
    - Oxygen saturation
    - Heart rate monitoring
- Staff performing and interpreting limited polysomnography at the central regional referral unit (RBHSC) should be able to demonstrate appropriate training and have suitable equipment.

Accessible

- There should be no unnecessary delays between diagnosis and definitive treatment.
- Children and young people failing first line treatments and deemed suitable for CPAP should have access to appropriate equipment and training in its use within 6 weeks (this should include backup technical and equipment support).

Effective

- All management should comply with current available evidence.
- A clinical database should be available. All data should be entered into the database to facilitate monitoring.

Efficient

- People deemed to be high risk should be prioritised for diagnostic screening.
- A tertiary paediatric OSAS clinic should be established at which people can avail of multidisciplinary input at one visit (including medical, surgical, dietetics, clinical psychology and play therapy).

Equitable

- There should be equal access to high quality care and appropriate investigation and management for all children with suspected OSAS.

Person Centered

- Improved formalised patient feedback should be developed and there should be consideration of how to measure patient reported outcome measures (PROMs).

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
All trusts should have a nominated clinician(s) who is be able to initiate and interpret investigation (e.g. oximetry) for suspected OSAS and make appropriate referrals (e.g. to ENT) of children with abnormal studies.	Trust report	100%	March 16
Percentage of children and young people with OSASH failing first line treatments who are deemed suitable for CPAP, who obtain access to appropriate equipment (with backup technical and equipment support) and training in its use within 2 weeks or 9 weeks, depending on level of urgency.	Regional database	95%	March 16
Percentage of children and young people with a diagnosis of OSAHS who have a named link respiratory nurse to access the multidisciplinary team at RBHSC.	Regional database	95%	March 16

6.9 LONG TERM VENTILATION IN ADULTS

Some people with severe conditions affecting their breathing may benefit from a type of breathing machine called a ventilator. In the past, the only way these could be used was by inserting a tube into the person’s windpipe. This meant the person had to stay in an intensive care unit. However, there are now types of ventilators that can deliver air into people’s lungs via a cushioned facemask. This is called non-invasive ventilation (NIV), as it does not require a tube to be inserted into the person’s body. It is often used only at night time, although the amount of time recommended varies depending on what condition the individual has.

One of the main advantages of NIV is that it can be provided by specialised doctors and nurses in an ordinary ward, and can also be given in the community if needed long-term. This means a person with a long-term condition requiring NIV is able to have it in their own home. To enable this, there needs to be support available and good communication between that person and the teams involved in their care.

The main conditions which NIV is used for are those which affect the chest and lungs, or the nerves and muscles involved in breathing. It is important that health professionals are able to identify people that might benefit from NIV, and that there is access to a specialist team to arrange this if it is needed.

People with muscle or nerve problems affecting their breathing may also have a reduced ability to cough properly. This makes it hard for them to clear their airways and can lead to chest infections. These people may benefit from a device that helps them to cough better, making them more comfortable and less prone to infection.

Overarching standard 37
All adults requiring, or potentially requiring long term ventilation, should have access to services that improve survival, enhance quality of life, avoid unplanned admissions to hospital and support their choice of end of life care.

Rationale:
Provision of coordinated complex home ventilation services prevents people from dying prematurely and enhances quality of life for people with long term conditions. Lack of coordinated care results in unnecessary acute admissions and use of high dependency unit and intensive care beds. Coordinated care allows end of life care needs to be met. Neurological and respiratory services need to work together closely to ensure that people have information about prognosis; shared decision making on issues of ceilings of care; advance care planning and preferred place of care where appropriate.

There are increasing indications for community NIV and markedly increasing numbers of people within Northern Ireland who require provision of coordinated regional and local services.

There is increasing evidence of the effectiveness of long term ventilation in obesity and in the treatment of some hypercapnic respiratory failure in some people with COPD.

Maintaining lung and chest wall compliance and ensuring an effective cough is crucial as respiratory compromise develops. Evidence based clinical guidelines support the use of cough augmentation techniques and devices. In people with low cough-flow rates, mechanical Insufflation-exsufflation (i.e. an assisted cough device) is the most effective modality for improving cough effectiveness, successfully reducing respiratory infections, hospitalisation, pneumonia and respiratory failure.

Evidence:
Radunovic A, Annane D, Rafiq MK, Mustfa N. Mechanical ventilation for amyotrophic lateral sclerosis/motor neuron disease. Cochrane Database Syst Rev. 2013 Mar 28; 3:CD004427. doi: 10.1002/14651858.CD004427.pub3. Review. PubMed PMID:23543531.

Annane D, Orlikowski D, Chevret S, Chevrolet JC, Raphaël JC. Nocturnal mechanical ventilation for chronic hypoventilation in patients with neuromuscular and chest wall disorders. Cochrane Database Syst Rev. 2007 Oct 17; (4):CD001941. Review. PubMed PMID: 17943762.

Maercker A, Perkonigg A, Preisig M, Schaller K, Weller M; Cost of Disorders of the Brain in Europe Study Group. The costs of disorders of the brain in Switzerland: an update from the European Brain Council Study for 2010. Swiss Med Wkly. 2013 Jan 7; 143:w13751. doi: 10.4414/smw.2013.13751. PubMed PMID: 23297120.

Hull J, Aniapravan R, Chan E, Chatwin M, Forton J, Gallagher J, Gibson N, Gordon J, Hughes I, McCulloch R, Russell RR, Simonds A. British Thoracic Society guideline for respiratory management of children with neuromuscular weakness.Thorax. 2012 Jul; 67 Suppl 1:i1-40. doi: 10.1136/thoraxjnl-2012-201964. PubMed PMID: 22730428.

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Bushby K, Finkel R, Birnkrant DJ, Case LE, Clemens PR, Cripe L, Kaul A, Kinnett K, McDonald C, Pandya S, Poysky J, Shapiro F, Tomezsko J, Constantin C;DMD Care Considerations Working Group. Diagnosis and management of Duchenne muscular dystrophy, part 2: implementation of multidisciplinary care. Lancet Neurol. 2010 Feb; 9 (2):177-89. doi: 10.1016/S1474-4422(09)70272-8. Epub 2009 Nov 27. Review. Erratum in: Lancet Neurol. 2010 Mar;9(3):237. PubMed PMID: 19945914.

Wang CH, Finkel RS, Bertini ES, Schroth M, Simonds A, Wong B, Aloysius A, Morrison L, Main M, Crawford TO, Trela A; Participants of the International Conference on SMA Standard of Care. Consensus statement for standard of care in spinal muscular atrophy. J Child Neurol. 2007 Aug; 22 (8):1027-49. PubMed PMID: 17761659.

Wang CH, Dowling JJ, North K, Schroth MK, Sejersen T, Shapiro F, Bellini J, Weiss H, Guillet M, Amburgey K, Apkon S, Bertini E, Bonnemann C, Clarke N, Connolly AM, Estournet-Mathiaud B, Fitzgerald D, Florence JM, Gee R, Gurgel-Giannetti J, Glanzman AM, Hofmeister B, Jungbluth H, Koumbourlis AC, Laing NG, Main M, Morrison LA, Munns C, Rose K, Schuler PM, Sewry C, Storhaug K, Vainzof M, Yuan N. Consensus statement on standard of care for congenital myopathies. J Child Neurol. 2012 Mar; 27 (3):363-82. doi:

10.1177/0883073812436605. PubMed PMID: 22431881.

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http://publications.nice.org.uk/motor-neurone-disease-cg105

The McCollum Report – Access to specialist neuromuscular care in Northern Ireland, July 2012, All-party group on muscular dystrophy in the Northern Ireland

Assembly http://www.muscular-dystrophy.org/assets/0003/5328/McCollum_Report.pdf

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Berg G, Delaive K, Manfreda J, Walld R, Kryger MH (2001) The use of health-care resources in obesity-hypoventilation syndrome. Chest 120: 377–38

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts

Quality Dimensions

Effective

- People with neuromuscular respiratory failure require access to a regional multidisciplinary team with specific expertise for review and outreach. This team should have neurological and respiratory consultant, nursing and physiotherapy representation.
- Provision of coordinated expert services improves survival and enhances quality of life.
- The regional team should coordinate care with the designated local leads, i.e. respiratory consultant, specialist respiratory nurse and specialist respiratory physiotherapist. This is particularly important with regards to unplanned acute admissions and where someone is unable to travel to a regional centre.
- Appropriate and timely use of cough augmentation techniques / devices can decrease hospital admissions due to respiratory problems.
- Access to palliative care services, where management of progressive neuromuscular respiratory failure is ineffective, facilitates quality end-of-life management and reduces unplanned admissions to secondary care.

Efficient

- Provision of coordinated expert services reduces unplanned admissions to hospital wards, high dependency units and intensive care units.

Equitable

- All people should have access to appropriate regional and local expertise for surveillance and management of neuromuscular respiratory failure.

Performance Indicator :	Data Source	Anticipated Performance Level	Date to be achieved by
Percentage of people who are at risk of neuromuscular respiratory failure, who have annual assessment of forced vital capacity (FVC) or equivalent (mouth or nasal pressures) and symptom check for neuromuscular respiratory failure and $Sp0_2$ measurement.	Neuromuscular clinics (prospective survey)	Baseline to be established Performance levels to be determined	March 16 March 17
Percentage of people with motor neurone disease who have a 3-monthly assessment of forced vital capacity (FVC) or equivalent (mouth or nasal pressures) and symptom check for neuromuscular respiratory failure and $Sp0_2$ measurement within the first 24 months of diagnosis (unless already on NIV).	Regional MND register	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of people with symptoms of neuromuscular respiratory failure or with FVC <50% (or inspiratory pressure < 40 cm water) sitting or lying, who are assessed and reviewed by a regional specialist multidisciplinary team (neurological and respiratory: medical, nursing & physiotherapy) every 6 months.	Regional database and Neuromuscular clinics (prospective survey)	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of people with complex needs on community long term ventilation who have	Regional database	Baseline to be established	March 17

access to support from a tertiary centre specialist respiratory nurse with expertise.		Performance levels to be determined	March 18
Percentage of people with complex needs on community long term ventilation who have access to support from a tertiary centre specialist respiratory physiotherapist with expertise.	Regional database	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of Trusts with named leads (respiratory physician, specialist respiratory nurse and specialist respiratory physiotherapist) to provide shared care support to people during acute admissions and for those who are unable to travel to regional services.	HSC Trust report	All Trusts	March 16
Percentage of Trusts with named leads (respiratory physician, specialist respiratory nurse and specialist respiratory physiotherapist) to provide support across acute and community for people with COPD and OSAHS and obesity hypoventilation syndrome.	HSC Trust report	All Trusts	March 16
Percentage of people who require cough augmentation equipment, who access it at time of discharge from hospital or within 4 months of decision to provide when being managed in the community.	Trust report	Baseline to be established Performance levels to be determined	March 17 March 18
Percentage of people with	Regional MND	50%	March 17

motor neurone disease who require cough augmentation equipment, who access it within 2 weeks of decision of clinical need.	register	70%	March 18
Percentage of people with symptomatic neuromuscular respiratory failure who have had the following (according to stage of illness): • Communication about prognosis • Shared decision making on ceilings of care • Advance care planning • Discussion on preferred place of care	HSC Trust report	Baseline to be established Performance levels to be determined	March 17 March 18

6.10 LONG TERM VENTILATION IN CHILDREN AND YOUNG PEOPLE

Some conditions are such that a child is unable to sustain adequate breathing or ventilation on their own and they need assistance or long term ventilation (LTV).

Children and young people who have experienced a traumatic spinal cord injury may never be able to breathe spontaneously and require LTV twenty fours each day. More commonly a group of children and young people who have progressive neuromuscular disorders, such as duchenne muscular dystrophy (DMD) or spinal muscular atrophy (SMA), require LTV to treat nocturnal hypoventilation (breathing which is inadequate while asleep) known as nocturnal non invasive ventilation (NIV). These children can breathe adequately during the day while awake, but the timely introduction of NNIV can rest the respiratory muscles at night and greatly improve day time quality of life. NIV is often beneficial before scoliosis surgery in children with DMD or SMA.

Children with weak respiratory muscles will also have weak coughing and be unable to clear secretions especially when suffering a respiratory infection. Modern physiotherapy with 'cough assist' techniques and devices is an equally important management tool.

LTV has an established track record in people with ventilatory failure. There are currently 52 children on LTV support in N Ireland. The numbers are likely to increase as the benefits of this treatment are realised for children with neuromuscular disease (NMD). Respiratory insufficiency is the most common cause of early death in children and adolescents with NMD. In the last decade nocturnal non invasive ventilation (NNIV) has considerably extended survival in children with these conditions and simultaneously vastly improved quality of life.

Standards of care have been drawn up for both DMD and SMA. These complex conditions require a multidisciplinary team approach involving a number of different specialties. These should be available at a one stop shop multidisciplinary outpatient clinic which should be based at the Royal Belfast Hospital for Sick Children, but delivered at the child's home.

Overarching Standard 38 – Assessment and support

All children and young people requiring or potentially requiring long term ventilation (LTV) or nocturnal non-invasive ventilatory (NNIV) support at home should have access to a specialist multidisciplinary team at tertiary level.

Rationale:

LTV has an established track record in children and young people with ventilatory failure (such as children with neuromuscular diseases). In some LTV involves 24 hour respiratory support (e.g. spinal cord injuries), while in the majority the goal is to treat nocturnal hypoventilation and thereby improve day time quality of life. Nocturnal non-invasive ventilation (NIV) is often beneficial before scoliosis surgery in children with duchenne muscular dystrophy and spinal muscular atrophy.

Successful home management of ventilator dependent children and young people can be traced to a smooth collaborative discharge from hospital to home and, once at home, a streamlined patient centred process with direct lines of communication. This is a complex discharge process which is impacts upon child and family life.

Cough assists are a new device with evidence based clinical guidelines recommending their use-age as safe and cost effective. Evidence supports their use in neuromuscular diseases and cervical spinal cord injury. Evidence also reports MI-E (cough assists) as the most effective modality for improving cough effectiveness, successfully reducing respiratory infections, hospitalisation, pneumonia and respiratory failure.

All young people with long term ventilator support should have appropriate arrangements in place for transition and transfer to adult services. Smooth transition from paediatric to adult services results in better adherence and clinical outcomes for young people.

Evidence:

NHS England. 2013/2014 NHS England Standard Contract for Paediatric Long Term Ventilation.
http://www.england.nhs.uk/wp-content/uploads/2013/06/e07-paedi-long-ventilation.pdf

Children on long-term ventilatory support: 10 years of progress. Wallis C, Paton JY, Beaton S, Jardine E. Arch Dis Child 2011; 96(11):998-1002
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Use of Mechanical Insufflation-Exsufflation as a cough augmentation technique for an ineffective cough – report for regional NIV group. Mc McCaughey J, Moran F (Unpublished)

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts

Quality Dimensions

Safe

- Children and young people who cannot breathe unaided should have appropriate monitoring to improve safety.
- Children and young people on LTV should have appropriate technical backup and support.
- Children and young people requiring LTV should have access to suitable inpatient studies to titrate respiratory support at least every 6 months, and more often if required.

Effective

- Children and young people potentially or requiring LTV should have access to:
  - ➢ physical and psychosocial assessment by a specialist multidisciplinary team which includes trained medical specialist nursing, physiotherapy, clinical psychology and access to support from social services and play therapy;
  - ➢ a clearly identified link respiratory nurse
- Children and young people with neuromuscular disease requiring LTV or NNIV should have access to a physiotherapist trained to meet their needs and familiar with cough assist techniques and devices.
- Children and young people with neuromuscular disease requiring LTV or NNIV should have access to cough augmentation equipment to maintain respiratory lung volumes, reduce need for intravenous antibiotics, improve quality of life, increase school attendance and reduce admissions.

Accessible

- Coordinated timely discharge leads to improved quality of life for the child/young person and family and greatly reduces unnecessary costs.
- All children and young people requiring long term invasive ventilation should be discharged to home or step-down care within 6 months of the decision to discharge providing they are medically stable, with appropriate carer training and support.

Performance Indicator:	Data source	Anticipated Performance Level	Date to be achieved by
Percentage of children and young people requiring NNIV/LTV who receive an initial assessment / management (within 4 weeks) and regular follow up (at least twice yearly) by the specialist regional multidisciplinary team.	RBHSC report Regional database Audit	80%	March 16
Percentage of children and young people requiring inpatient sleep studies who are admitted within 13 weeks.	RBHSC trust report	60% 90% 100%	March 16 March 17 March 18
Percentage of children and young people requiring long term ventilation where the decision has been made to discharge to home or step-down care who are discharged within 6 months.	RBHSC trust report	70% 80% 90%	March 16 March 17 March 18
Percentage of children and young people starting ventilatory support and at critical periods who have specific play therapy input to support and optimise compliance.	RBHSC trust report	Baseline to be established Performance levels to be determined	March 16 March 17
Percentage of children who require cough augmentation equipment, who access it within 4 months of decision to provide.	RBHSC trust report	50% 100%	March 16 March 18

Percentage of children and young people whose initial and essential investigations and treatment, as part of evidence based pathways, are coordinated in clinically appropriate times.	RBHSC trust report	20% 40% 60%	March 16 March 17 March 18
Percentage of children and young people who require psychology support who receive it from a nominated psychologist with an interest in respiratory disease, within 15 weeks.	RBHSC trust report	Baseline to be established Performance levels to be determined	March 16 March 17

6.11 CYSTIC FIBROSIS

Cystic fibrosis is an inherited disorder caused by a faulty gene. The underlying disorder in cystic fibrosis leads to the production of sticky secretions. This affects internal organs such as the lungs and digestive tract, which can lead to frequent chest infections and problems digesting food.

One in twenty people in the population carries the gene for cystic fibrosis. If two carriers of the gene have children they have a one in four chance of having a child with cystic fibrosis. Most cases of CF in the UK are now diagnosed soon after birth.

There are almost 500 people with cystic fibrosis diagnosed in Northern Ireland. All of these people attend the specialist adult and paediatric cystic fibrosis centres in Belfast. A multidisciplinary approach to care improves outcomes in cystic fibrosis. This is delivered by a specialist team which includes doctors, nurses, dieticians, physiotherapists and social workers.

Early diagnosis (by screening all newborn babies and carrying out the correct tests at the specialist centre) means that appropriate management can be started at an earlier age. As a result of this, as well as improvements in care, people with cystic fibrosis are living longer. However, this means that their physical and psychological needs are increasing. It is important that people with CF and their carers are supported, and that young people are supported in their move from children’s services to adult services.

Overarching standard 39

All newborn babies in Northern Ireland should be offered screening for cystic fibrosis.

Rationale:

Early diagnosis and appropriate referral reduces morbidity and mortality in cystic fibrosis, and newborn screening for CF has been shown to be cost-effective.

Evidence:

European best practice guidelines for cystic fibrosis neonatal screening. Castellani, Carlo, et al. "European best practice guidelines for cystic fibrosis neonatal screening." *Journal of Cystic Fibrosis* 8.3 (2009): 153-173. https://www.ecfs.eu/files/webfm/webfiles/File/documents/Castellani_2009_Journal-of-Cystic-Fibrosis.pdf

UK National Screening Committee – Standards for Newborn Blood Spot Screening http://newbornbloodspot.screening.nhs.uk/standards

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Regional Newborn Screening Laboratory
Regional Genetics Laboratory
Primary Care

Quality Dimensions

Safe
Evidence suggests that the benefits outweigh the harms (e.g. anxiety) (Castellani et al. 2009). Those involved in the screening programme (for example conducting heel prick, laboratory testing, and explaining results) should have appropriate training.

Accessible
Early diagnosis, communication of results and rapid referral (if appropriate) minimises anxiety and early diagnosis improves outcomes. There should be no unnecessary delays.

Effective
The programme is based on UK National Screening Committee guidance

Efficient
Evidence suggests that newborn screening is cost effective. There is a national system in place for quality assurance and performance management.

Equitable
The aim is for universal coverage. IRT/DNA testing may not identify people with mutations specific to some ethnic origins and this should be taken into account.

Person Centred
This standard aims to ensure early diagnosis and effective intervention to provide the best care for people and their carers.

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of babies born in Northern Ireland (and still resident) with conclusive blood spot screening result recorded on Child Health System by 17 days of age.	Child Health System	UK standard from April 2014) TBC	March 16 March 17 March 18

Overarching standard 40
All people suspected of having cystic fibrosis should have appropriate diagnostic testing at a specialist centre.

Rationale:
Early diagnosis, referral and intervention improves health outcomes in cystic fibrosis.

Evidence:
European best practice guidelines for cystic fibrosis neonatal screening. Castellani, Carlo, et al. "European best practice guidelines for cystic fibrosis neonatal screening." *Journal of Cystic Fibrosis* 8.3 (2009): 153-173. https://www.ecfs.eu/files/webfm/webfiles/File/documents/Castellani_2009_Journal-of-Cystic-Fibrosis.pdf

UK National Screening Committee – Standards for Newborn Blood Spot Screening http://newbornbloodspot.screening.nhs.uk/standards

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Regional Newborn Screening Laboratory
Regional Genetics Laboratory
Paediatric and Adult Cystic fibrosis centres
Biochemistry Laboratories

Quality Dimension
Safe Regional cystic fibrosis units (adult and paediatric) are peer monitored for quality assurance and provide multi-disciplinary assessment. **Accessible** Ensuring prompt referral minimises parental/patient anxiety and early intervention improves outcomes – there should be no avoidable delays. **Effective** Evidence supports early diagnosis and intervention. Clinical outcome measures for patients (including lung function, sputum microbiology and BMI) are recorded on patient registry and annual reports generated comparing UK centres. **Efficient** Early intervention is associated with a reduced burden of care later in life in CF; therefore early diagnosis is cost effective and improves patient outcomes. **Equitable** All children and adults with a suspected diagnosis of CF should be referred to the appropriate specialist centre and have access to all the appropriate diagnostic tests. **Person Centred** People with CF should receive appropriate care from specialist teams that will improve their health outcomes and provide psychological/social support as needed.

Performance Indicator	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of babies suspected of having cystic fibrosis (2 mutations identified) should have their first clinical appointment with the cystic fibrosis team by 28 days of age.	CF registry & Adult and Paediatric CF centres UK standard from April 2014)	Acceptable 95% Achievable 100%	March 16 March 17 March 18
Percentage of babies suspected of having cystic fibrosis (1 mutation identified + second IRT positive OR no mutations identified + second IRT positive) should have their first clinical appointment with the cystic fibrosis team by 35 days of age.	CF registry & Adult and Paediatric CF centres UK standard from April 2014)	Acceptable 80% Achievable 100%	March 16 March 17 March 18

Overarching standard 41
All people with cystic fibrosis should receive care from a specialist centre delivered by a specialist multidisciplinary team. Care should be in line with best practice guidelines.

Rationale:
Specialist centre care improves quality of life and survival of people with cystic fibrosis.

Evidence:
CF Trust Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (December 2011)
https://www.cysticfibrosis.org.uk/media/82070/CD_Standards_of_Care_Dec_11.pdf

Kerem E, Conway S, Elborn S, Heijerman H; Standards of care for patients with cystic fibrosis: a European consensus. J Cyst Fibros. 2005 Mar;4(1):7-26
http://www.elsevier.com/framework_products/promis_misc/2005.pdf

CF Trust Standards of Care and Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis
https://www.cysticfibrosis.org.uk/media/82076/CD_Standards_of_Care_Physio_Jun_11.pdf

CF Trust Standards for Nutritional Management of Cystic Fibrosis
https://www.cysticfibrosis.org.uk/media/82052/CD_Nutritional_Management_Apr_02.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Paediatric and Adult Cystic Fibrosis Centres

Quality Dimension

Safe
Cystic fibrosis centres are peer reviewed and the multidisciplinary team consists of specialists in CF management.

Accessible
Newborn screening should contribute to ensuring early diagnosis and referral. A thorough annual assessment is undertaken for all people and frequency of review based on need.

Effective
Specialist centre care has been shown to improve quality of life and survival of people with cystic fibrosis. This will be reflected in outcome measures such as lung function and BMI which are recorded on the registry, for which a UK wide report is published annually by the Cystic Fibrosis Trust allowing comparisons of outcomes over time and between centres.

Efficient
A multidisciplinary clinic enables people with cystic fibrosis to access medical, nursing, dietetic and social support during one visit.

Equitable
All people with cystic fibrosis in Northern Ireland should be managed from the regional specialist centres, regardless of where they live.

Person Centred
Care for people with cystic fibrosis should be provided by a specialist multi-disciplinary team which can identify and address physical, psychological and social needs and communicate appropriately and effectively.

Performance Indicator:	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of adults who have the following data recorded annually: • FEV$_1$ % predicted • BMI • Sputum microbiology	CF registry	90%	March 17
2a) Percentage of children who have the following data recorded annually: • BMI centile or weight centile for those <2 • Sputum microbiology 2b) Percentage of children >5 years old who can perform spirometry who have FEV1 % predicted recorded annually.	CF registry	90% (2a and 2b)	March 17
Percentage of people reporting satisfaction with communication /information received from the specialist team.	Adults: Patient questionnaire (to be developed in conjunction with patient advocate)	90%	March 16
	Children: Peer review due Feb 2014	90%	March 16

Overarching standard 42
All people with cystic fibrosis should have their care provided in a safe environment consistent with infection control policies.

Rationale:
Effective infection control reduces the number of people with cystic fibrosis infected with bacteria associated with poorer outcomes.

Evidence:
CF Trust Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK (December 2011)
https://www.cysticfibrosis.org.uk/media/82070/CD_Standards_of_Care_Dec_11.pdf

The *Burkholderia cepacia* complex – Suggestions for prevention and infection control. Second edition (September 2004)
http://www.cftrust.org.uk/aboutcf/publications/consensusdoc/C_Burkholderia_cepacia_Sep_2004.pdf

Pseudomonas aeruginosa infection in people with cystic fibrosis. Suggestions for prevention and infection control. Second edition (November 2004)
http://www.cftrust.org.uk/aboutcf/publications/consensusdoc/C_Pseudomonas_aeruginosa_Nov_04.pdf

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Paediatric and Adult Cystic Fibrosis Centre

Quality Dimensions

Safe
It is important to minimise the spread of infection between people and from the clinical environment.

Effective
Infection control policies should be based on CF Trust standards and guidelines. Effectiveness will be reflected in lack of cross infection, as identified by sputum microbiology.

Performance Level:	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of people receiving microbiological surveillance of at least 4 samples (sputum or cough swab) per year.	Cystic Fibrosis centres (adult & children) & CF clinical microbiologist report	85%	March 17
Percentage of inpatients in single room accommodation.	CF centres report	100%	March 16

6.12 BRONCHIECTASIS

Bronchiectasis is a term used to describe a particular type of airway damage. Normally the branches of the lungs get smaller as they go further out in the lungs, like the branches of a tree. In bronchiectasis these tubes become widened and this allows secretions to gather. The stretched tube then becomes a reservoir of secretions become easily infected.

There are a number of different causes of bronchiectasis. Sometimes a scar from an old wound can stretch the remainder of the lung and distort the bronchi (tubes). This is common after tuberculosis infection. Other structural causes of bronchiectasis include whooping cough. Some conditions are associated with altered immunity and poor ability to fight infections. Others are associated with a failure to clear secretions. Usually microscopic hairs, called cilia, move secretions along the airway to the top of the lung. In primary ciliary dyskinesia the fibres do not work well and secretions gather and infections occur. The most common cause for altered secretions is cystic fibrosis.

There are likely to be around 5,000 people in Northern Ireland with bronchiectasis, resulting in 300 to 500 admissions per year. It is important that people (children and adults) are properly assessed to confirm a diagnosis of bronchiectasis. The infections in bronchiectasis can be difficult to treat. They often require prolonged courses of antibiotics given by injection. Daily physiotherapy is needed to clear excessive secretions. Written individualised self-management plans support people to manage their own or their child’s condition. Care for those with bronchiectasis by a specialist respiratory team reduces the effects of the disease and cuts down the number of admissions to hospital and the length of stay in hospital if someone has to be admitted. This team can make sure that the correct investigations and management are carried out.

Overarching standard 43
All people with suspected bronchiectasis should be investigated in line with BTS guidance.

Rationale:
A significant proportion of people with a chronic productive cough have bronchiectasis. A comprehensive assessment is necessary to establish the diagnosis and direct management.

Evidence:
BTS Quality Standards for Clinically Significant Bronchiectasis in Adults (2012)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

British Thoracic Society (BTS) Guidelines for non-CF Bronchiectasis (2010)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

Bradley J, Lavery K, Rendall J, Elborn JS. Managing bronchiectasis. Practitioner. 2006 Apr;250(1681):194, 197, 199-200.

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Primary care

Quality Dimension

Safe

- All those with suspected bronchiectasis should be referred to a respiratory physician/paediatrician for investigations to confirm diagnosis.

Accessible

- There should be no unnecessary delays in establishing a diagnosis.

Effective

- In keeping with BTS guidelines, people with a clinical diagnosis of bronchiectasis should have the diagnosis confirmed by high resolution CT chest. They should also be investigated for:
    - Allergic bronchopulmonary aspergillosis
    - Common variable immunodeficiency
    - Cystic fibrosis (all individuals <40 years old and considered in >40 for those indicated by BTS guidance)
- The following conditions should also be considered:
    - Gastro-oesophageal reflux disease/hiatus hernia
    - Coeliac Disease
    - Connective tissue disorders
    - Foreign body aspiration
    - Congenital e.g. primary ciliary dyskinesia
    - TB

Equitable

- All individuals with suspected bronchiectasis should have access to the investigations recommended in BTS guidelines 2012.

Performance Indicator:	**Data source**	**Anticipated performance level**	**Date to be achieved by**
ADULTS			
Percentage of people with clinical diagnosis of bronchiectasis who have had diagnosis confirmed by high resolution CT chest.	BTS audit	90%	March 16
Percentage of people with a clinical diagnosis of bronchiectasis who have been investigated for: • Allergic bronchopulmonary aspergillosis • Common variable immunodeficiency • Cystic fibrosis in up to all individuals <40 years old (and considered in >40 for those indicated by BTS guidance)	BTS audit	40% 60%	March 16 March 17
CHILDREN Percentage of children and young people with suspected bronchiectasis who have the appropriate investigations completed as per the BTS guidelines in tertiary care.	BTS Paediatric Bronchiectasis Audit RBHSC	80% of children meet the diagnostic criteria 100%	March 16 March 18

Overarching standard 44
All people with clinically significant bronchiectasis should be accurately assessed and managed by a multidisciplinary respiratory team including a consultant, physiotherapist and nurse with a special interest in bronchiectasis.

Rationale:
Clinically significant bronchiectasis is defined by BTS as a clinical syndrome of regular cough and sputum production, with or without recurrent chest infections and radiological confirmation of bronchiectasis. Care for people with clinically significant bronchiectasis by a specialist respiratory team reduces morbidity and frequency of hospital admission in those with moderate to severe disease. Inpatient care by the specialist respiratory team reduces length of stay and the likelihood of readmission.

Regular airway clearance is regarded as a key component in the management of bronchiectasis because it may improve symptoms and reduce exacerbation frequency. For people with complex circumstances, management plans can support adherence to treatment regimes.

Evidence:
BTS Quality Standards for Clinically Significant Bronchiectasis in Adults (2012)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

British Thoracic Society (BTS) Guidelines for non-CF Bronchiectasis (2010)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

Bradley J, Lavery K, Rendall J, Elborn JS. Managing bronchiectasis. Practitioner. 2006 Apr;250(1681):194, 197, 199-200.

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts

Quality Dimensions

Safe

- All adults with clinically significant bronchiectasis should be reviewed at least annually by a designated respiratory physician within the context of a specialist respiratory multidisciplinary team. For each trust, the Specialist Respiratory Team should include a:
    - Consultant with specialist interest in bronchiectasis
    - Physiotherapist with a specialist interest in bronchiectasis
    - Respiratory nurse with a specialist interest in bronchiectasis
- All children and young people should be looked after by a multidisciplinary team which includes a consultant, physiotherapist and nurse specialist; with access to psychology, pharmacy, social services and dietetic support, all of which should have expertise in bronchiectasis care.

Accessible

- All individuals should have timely access to assessment and treatment at home or in hospital under a specialist respiratory team where indicated.
- Children with poorly controlled symptoms or exacerbations should be admitted to hospital under the care of the respiratory team in a timely fashion.

Effective

- Management under the specialist respiratory multidisciplinary team while stable should include:
    - Education regarding appropriate airway clearance techniques by a specialist respiratory physiotherapist
    - Sputum microbiology sent and recorded at least annually while stable
- Management during exacerbation should include:
    - An objective evaluation of the efficacy of their treatment with the result recorded
    - Appropriate investigations before and after IV antibiotic therapy course, which may include sputum microbiology, inflammatory markers and spirometry
    - Consideration of home IV therapy if suitable
- People with breathlessness affecting activities of daily living should be referred to pulmonary rehabilitation. There should be services to facilitate provision of nebulised prophylactic antibiotics for suitable people, supervised by a respiratory specialist.

Efficient

- Sputum bacteriological culture should be obtained annual from individuals with bronchiectasis when stable to identify presence of colonising organisms and also prior to empirical antibiotic therapy to guide clinicians in appropriate antibiotic choice. This should not occur at the expense of prompt commencement of antibiotics therapy.

Equitable

- Individuals with bronchiectasis should have access to specialist, multidisciplinary care regardless of their locality.

Person Centred

- People with bronchiectasis should be supported to take an active role in managing their condition, for example provision of sputum pots and envelopes at clinic to facilitate submission of samples.
- There should be services in place to enable individuals with bronchiectasis to be offered and supported to receive home IV therapy for exacerbations where appropriate. This will require a robust community team for delivery of IV antibiotics (rapid response) and domiciliary physiotherapy provision if required.

Performance Indicator	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
ADULTS Stable			
Number of trusts with access to a specialist respiratory team comprising at least a respiratory clinician, respiratory specialist nurse and a physiotherapist with a special interest in bronchiectasis.	HSC Trusts	All	March 15
Percentage of individuals diagnosed with bronchiectasis who have been reviewed by a respiratory physiotherapist.	BTS audit	90%	March 16
Percentage of individuals with a diagnosis of bronchiectasis who had sputum bacteriology culture when clinically stable sent and recorded within the last 12 months.	BTS audit	80%	March 16
Percentage of individuals with breathlessness affecting activities of daily living referred to pulmonary rehabilitation.	BTS audit	60% 80%	March 16 March 18

Exacerbations			
Percentage of individuals with an exacerbation of bronchiectasis who have a sputum sample sent for microbiological culture prior to empirical treatment.	BTS audit	80%	March 16
Percentage of individuals with an exacerbation of bronchiectasis with an objective evaluation of efficacy (at least one of bacteriology, inflammatory markers or spirometry).	BTS audit	80%	March 16
Percentage of individuals with an exacerbation of bronchiectasis who are offered home IV therapy where appropriate.	BTS audit	60% 80%	March 16 March 18

CHILDREN TERTIARY CARE			
Stable			
Percentage of children and young people with symptomatic disease who attend a one-stop-shop multidisciplinary service.	HSC Trust report	100%	March 16
Percentage of children and young people who have a comprehensive annual review to include spiromotery, BMI centile and sputum microbiology where appropriate.	BTS paediatric audit	90%	March 16
Percentage of children and young people who have regular microbiological surveillance every 3 months.	BTS paediatric audit	60% 90%	March 16 March 18

Exacerbations			
Percentage of children and young people with poorly controlled symptoms or exacerbations who are admitted within 72 hours of the decision to admit.	RBHSC report	100%	March 16 March 17
Percentage of children and young people admitted with bronchiectasis for IV antibiotics who have therapy started within 24 hours of admission.	RBHSC report	100%	March 16

Overarching standard 45 – Education and self-management
All individuals with symptomatic bronchiectasis and their carers should be given the opportunity to learn about their disease and receive individualised self-management information.

Rationale:
Individuals with bronchiectasis, and their carers, should be given greater control over their lives by ensuring that knowledge of their condition is developed to a point where they can take responsibility for its management and be enabled to work in partnership with their health and social care providers.

The development of an individualised written self-management is intended to allow people with bronchiectasis to manage their condition and to recognise, respond to and reduce the occurrence of exacerbations. The use of self-reported antibiotic diaries may be useful to provide the secondary care MDT with an objective indication of exacerbation frequency.

Evidence:
BTS Quality Standards for Clinically Significant Bronchiectasis in Adults (2012)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

British Thoracic Society (BTS) Guidelines for non-CF Bronchiectasis (2010)
http://www.brit-thoracic.org.uk/Guidelines/Bronchiectasis-Guideline-non-CF.aspx

Self-management in bronchiectasis. An exploratory randomised controlled trial of a disease specific expert individual programme compared to usual care in individuals with bronchiectasis. Lavery, O'Neill, Parker, Elborn, Bradley. Arch Phys Med Rehabil. 2011 Aug;92(8):1194-201.
http://www.ncbi.nlm.nih.gov/pubmed/21807138

Self-management in bronchiectasis: the patients' perspective. Lavery, O'Neill, Parker, Elborn, Bradley. European Respiratory Journal 29.3 (2007): 541-547.
http://www.ncbi.nlm.nih.gov/pubmed/17079260

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts

Quality Dimensions

Accessible

- Provision of self-management information should enable individuals to identify symptoms of an exacerbation and seek help in a timely manner.

Effective

- A system should be established to ensure that individuals who have symptomatic bronchiectasis attending secondary care have been given individualised, face-to-face information and a written action plan.

Equitable

- Pulmonary rehabilitation programmes in each trust should be able to provide bronchiectasis specific information for those with bronchiectasis.

Person Centred

- Information and self-management plans should be individualised to reflect each person's needs and circumstances.

Performance Indicator	**Data Source**	**Anticipated Performance Levels**	**Date to be achieved by**
Percentage of adults attending secondary care who have been given individualised, face-to-face information and a written action plan.	HSC Trusts	60%	March 16

6.13 INTERSTITIAL LUNG DISEASE (ILD)

The interstitial lung diseases (ILDs) are a collection of conditions that cause inflammation and/or scarring within the lungs. This results in increasing shortness of breath, cough and widespread shadowing on chest x-ray. Some ILDs have a known cause such as asbestosis, bird fancier's lung and farmer's lung. ILD is also found in association with connective tissue diseases such as rheumatoid arthritis and scleroderma. However, in many cases the cause is unknown. The three most common forms of ILD are idiopathic pulmonary fibrosis (IPF), sarcoidosis, and hypersensitivity pneumonitis. Approximately 90 cases of IPF and 200 cases of sarcoidosis are expected in Northern Ireland each year.

The investigation of a person suspected of having ILD should include a clinical assessment led by a consultant respiratory physician with a special interest in ILD. Specialised breathing test are needed which should be carried out by trained respiratory physiologists. CT scanning of the lungs is usually required and should be interpreted by a radiologist with an interest in respiratory imaging and informed by discussion with the referring respiratory physician.

Biopsies of the lung may be needed for diagnosis in some people. These may be performed through a fibre optic bronchoscope. Some cases require surgical lung biopsy either through a keyhole through the chest wall or open surgery. Biopsies should be interpreted by a histopathologist with an interest in respiratory pathology and informed by discussion with the referring respiratory physician.

A diagnosis of idiopathic pulmonary fibrosis (IPF) should only be made following discussion by a multidisciplinary team (MDT) for interstitial lung disease. Complex cases should be referred to a regional specialist ILD centre for discussion or further clinical assessment.

Following MDT diagnosis of IPF, people may be considered for treatment with Pirfenidone or other NICE-approved therapies. The treatment of other ILDs may include the use of corticosteroids and cytotoxic drugs which can have serious side effects so that their use needs monitored with particular care. A small number of cases may be suitable for lung transplant.

There should be a specialist nurse with an interest in interstitial lung disease available at all stages to provide information and support to people with ILD and their families and carers.

Some types of ILD can progress and cause shortness of breath which does not respond to drug treatment. Specialist respiratory teams should be available to people to help them and their carers deal with their palliative care needs.

Overarching standard 46 – Diagnostic Processes for Interstitial Lung Disease

People with known or suspected ILD should be under the care of a respiratory multidisciplinary team for interstitial lung disease.

Rationale:

ILDs comprise a wide spectrum of pathologies and presentations. Accurate diagnosis is essential due to variation in treatment strategies and prognosis between different ILDs. People suspected of having ILD should be diagnosed and managed by staff with the appropriate training and skills. They should be managed under the care of a multidisciplinary team led by a consultant respiratory physician with an interest in Interstitial lung disease. The ILD team should have appropriate physiological, radiological, pathological, surgical and laboratory support. A diagnosis of idiopathic pulmonary fibrosis should only be made following the consensus of an ILD multidisciplinary team (MDT). Where a confident diagnosis cannot be made by the MDT, people should be considered for surgical lung biopsy with the agreement of the thoracic surgeon. There should be a designated regional lead in ILD available to provide tertiary support and to develop and coordinate services.

Evidence:

National Institute for Health and Clinical Excellence (NICE) (CG 163, June 2013) Diagnosis and management of suspected idiopathic pulmonary fibrosis.
http://publications.nice.org.uk/idiopathic-pulmonary-fibrosis-cg163

British Thoracic Society Interstitial Lung Disease Guideline Group. Interstitial lung disease guideline. Thorax 2008; 63 (Suppl V):v1-v58.
http://www.brit-thoracic.org.uk/portals/0/guidelines/dpldguidelines/thorax%20sept%2008.pdf

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts (including respiratory physicians, clinical physiologists, radiologists, pathologists and thoracic surgeons).

Quality Dimension

Safe

- People are managed by a team of health professionals, who each have a special interest in the management of ILD. Consensus agreement of an ILD MDT will be required for referral for surgical lung biopsy and for a diagnosis of IPF to be made. People will have access to NICE-approved therapies.
- The ILD team should have on-site pulmonary function testing conforming to BTS/ARTP standards including spirometry, lung volumes and transfer factor and have access to cardiopulmonary exercise testing. Pulmonary function testing should be performed by a clinical physiologist with training in respiratory physiology.

Accessible

- People referred for High Resolution CT scans (HRCT) of the chest should have scans performed and reported within 4 weeks.
- People suspected of having ILD should have initial investigation with lung function and HRCT, with subsequent MDT discussion completed to allow review with management plan in less than 6 weeks from first clinic visit.
- People undergoing biopsy procedures should have MDT discussion of results and review at OPD within 2 weeks of procedure.

Effective

- The investigation and management of people is informed by national best practice guidance.
- All people suspected of having ILD should be referred to a multidisciplinary respiratory team with expertise in ILD.
- A diagnosis of idiopathic pulmonary fibrosis (IPF) should only be made with the consensus of a multidisciplinary team (MDT) An ILD MDT should include a consultant respiratory physician with an interest in ILD, a consultant radiologist with an interest in thoracic imaging, a specialist nurse with an interest in interstitial lung disease and a team coordinator as core members, with input from a consultant histopathologist and consultant thoracic surgeon as appropriate.
- There should only be one or two consultant respiratory physicians per Trust registered to prescribe Pirfenidone.
- Complex cases should have access to a regional specialist ILD centre for further assessment.
- Where MDT cannot make a confident diagnosis, people should have access to bronchoalveolar lavage (BAL), transbronchial biopsy or surgical lung biopsy with results to be re-discussed at MDT meeting.
- People should have access to pulmonary rehabilitation, including

assessment by 6-minute walk test, and quality of life assessment.
- People should have access to NICE-approved therapies and should be offered supportive care including palliative services as appropriate.

Person centred

- Investigation and diagnosis will be carried out within a specified time frame. People will be provided with accurate written and verbal information about their condition and will have access to information and support through the ILD specialist nurse.
- An interstitial lung disease specialist nurse should be available at all stages of the care pathway to provide information and support to people and to their families and carers with the person's consent.
- People should receive accurate and clear information about investigations, diagnosis and management.

Efficient

- Accuracy of diagnosis is essential to ensure best use of possible treatments.

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of Trusts who have local access to a radiologist with expertise in thoracic imaging.	Trust report	100%	March 17
Percentage of Trusts who have regional access to a pathology service with appropriate expertise in ILD.	Trust report	100%	March 17
Percentage of Trusts with a named lead consultant respiratory physician with an interest in ILD.	Trust report	100%	March 16
Percentage of Trusts with a named specialist respiratory nurse with an interest in ILD.	Trust report	100%	March 17
Percentage of people with suspected ILD / IPF who have had case discussion at a local multidisciplinary team meeting for ILD.	ILD database (to be developed)	50%	March 18
Percentage of people with ILD / IPF who have been assessed as per the evidence based pathway, at a regional centre for Pirfenidone and other novel therapies.	ILD database (to be developed)	Baseline to be established	March 18

7. STANDARDS RELATING TO ALL CONDITIONS

7.1 PULMONARY REHABILITATION

Pulmonary rehabilitation is a dynamic multidisciplinary programme of care consisting of exercise, education and psychosocial interventions. It can be tailored to individual need and is designed to improve physical and social performance and sense of control for people with chronic respiratory disease.

The benefits of pulmonary rehabilitation have been well researched and it has been shown to improve quality of life, reduce breathlessness, increase function and exercise capacity, and decrease the use of health services. Pulmonary rehabilitation has been identified as a central treatment strategy for COPD particularly.

Pulmonary rehabilitation programmes should meet the standards that have been shown in research studies to be necessary for the person to achieve evidence based outcomes. These standards define various multidisciplinary aspects and the number of sessions that a person should attend.

Pulmonary rehabilitation should also incorporate enhanced supported self-management.

There should also be opportunity for people to attend other exercise programmes and social support programmes in the community to help them maintain the outcomes achieved during pulmonary rehabilitation.

Overarching standard 47
All people with respiratory conditions who can benefit from pulmonary rehabilitation should be offered this by their GP or specialist respiratory team.

Rationale:
Pulmonary rehabilitation delivered, by a multidisciplinary team, has been convincingly demonstrated to improve the symptoms of chronic respiratory disease including exercise capacity, breathlessness, health status and psychological wellbeing.

People with respiratory conditions and who are functionally limited by breathlessness (MRC 3-5) should be offered pulmonary rehabilitation.

Other people with respiratory conditions, with functional limitations due to their respiratory condition may be considered e.g. Bronchiectasis, COPD MRC Grade 2.

People with COPD with recent hospitalisation for an exacerbation should be offered/referred PR to commence within 1 month of discharge, as it can reduce hospital readmissions.

References:

Bolton CE, Bevan-Smith EF, Blakey JD, et al. British Thoracic Society guideline on pulmonary rehabilitation in adults Thorax 2013;68:ii1–ii30

National Clinical Guideline Centre. Chronic obstructive pulmonary disease: management of chronic obstructive pulmonary disease in adults in primary and secondary care. London: National Clinical Guideline Centre; 2010 Available from: http://guidance.nice.org.uk/CG101/Guidance/pdf/English.

Ries AL, Bauldoff GS, Carlin BW et al. Pulmonary rehabilitation: joint ACCP/AACVPR evidence-based clinical practice guidelines. Chest 2007; 131(suppl) (5):4S-42S (Executive Summary 1S-3S).

Cosgrove D, MacMahon J, Bourbeau J, Bradley JM, O’Neill B. Facilitating education in pulmonary rehabilitation using the Living Well with COPD programme for pulmonary rehabilitation: a process evaluation. *BMC Pulmonary Medicine* 2013, **13**:50 doi:10.1186/1471-2466-13-50

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Integrated Care Partnerships (ICPs)
Primary Care

Quality Dimensions

Safe

- People should be appropriately selected for pulmonary rehabilitation; exclusion criteria may include the presence of unstable cardiac disease, musculoskeletal or neurological difficulties which would prevent exercise, people in a terminal phase of their illness or the presence of significant cognitive or psychiatric impairment.
- Assessment should be completed as the initial component of enrolment on the programme in line with the BTS Guidelines for Pulmonary Rehabilitation (2013).
- A supervised pulmonary rehabilitation programme is recommended for people with COPD.
- Pulmonary Rehabilitation should be delivered by the specialist respiratory MDT who are appropriately trained.

Accessible

- People with respiratory conditions and who are functionally limited by breathlessness (MRC 3-5) should be offered pulmonary rehabilitation within 3 months of referral.
- People with COPD with recent hospitalisation for an exacerbation should be offered pulmonary rehabilitation to commence within 1 month of discharge.
- Other people with respiratory conditions with functional limitations due to their respiratory condition may be considered e.g. Bronchiectasis, COPD MRC Grade 2.
- Repeat pulmonary rehabilitation should be considered in people who have completed a course of pulmonary rehabilitation more than 1 year previously.

Effective

- Pulmonary rehabilitation programmes should be provided according to the BTS 2013 guidelines for PR (2013).
- Assessment for Pulmonary rehabilitation should consider measurement of exercise capacity, breathlessness, health status and psychological wellbeing.

Efficient

- To ensure the delivery of pulmonary rehabilitation to all the target populations, innovative models may need to be explored which consider efficient use of resources, safety and outcomes.

Equitable

- All people completing pulmonary rehabilitation should be encouraged to continue to exercise beyond the programme.

Person Centred

- Pulmonary Rehabilitation should be held at times that suit people and in buildings that are easy for them to get to and have good access for those with disabilities.
- Pulmonary rehabilitation programmes should be geographically accessible.
- Pulmonary rehabilitation programmes should be tailored to the needs and ability of each individual.
- As part of regular assessment, patient satisfaction and feedback should be sought.

Performance indicator:	Data Source	Anticipated Performance Levels	Date to be achieved by
Percentage of people with COPD who meet the criteria for pulmonary rehabilitation and have been offered referral for pulmonary rehabilitation.	Regional LES and HSC Trust report	50%	March 17
Percentage of pulmonary rehabilitation programmes which are geographically accessible i.e. within 30 minutes of travel.	HSC Trust report	100%	March 16
Percentage of pulmonary rehabilitation programmes which include all required elements as per BTS guidelines.	HSC Trust report	100%	March 16
Percentage of pulmonary rehabilitation programmes which have a mechanism to provide support to people for on-going exercise and social support for those who need this.	HSC Trust report	100%	March 16

7.2 TRANSITIONAL CARE FOR ADOLESCENTS WITH CHRONIC RESPIRATORY DISEASE

Transitional care refers to the period during which young people with respiratory disease move from child to adult services. It is important that planning for this starts early and that the transitional process is well co-ordinated. The young person and their parents/carers should be adequately supported throughout the process and involved in decision making. When transitional care is done well, it ensures that young people receive care that is appropriate for their age and helps to promote independence.

This standard has been developed to ensure that there are proper arrangements in place to ensure a smooth transition and support young people and their families at this time of change.

Overarching standard 48
All young people with chronic respiratory disease (difficult asthma / OSAS / LTV / cystic fibrosis / bronchiectasis) should have appropriate arrangements in place for transition for transfer to adult services.

Rationale:
Moving from paediatric to adult services can be a difficult time for young people and their parents/carers. A co-ordinated, person-centred approach can help to promote independence in young people with chronic respiratory disease and lead to better adherence and clinical outcomes. Dedicated transitional clinics/systems facilitate this process.

During this period, the young person's general practitioner has an important role as a constant element of the young person's care pathway. It is essential that they are kept up to date with the transition process and receive written information from the secondary care teams, including contact details for the respiratory service.

Evidence:
Transition from paediatric to adult care: A guide for commissioners, hospital and clinical teams. Cystic Fibrosis Trust March 2013

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK. Cystic Fibrosis Trust 2011

Bridging the Gaps: Health Care for Adolescents. Royal College of Paediatrics and Child Health June 2003

Responsibility for delivery / implementation:

Public Health Agency
HSC Board
HSC Trusts
Belfast Regional Respiratory Service
Paediatric and Adult Cystic Fibrosis Centres
Primary Care
ICPs

Quality Dimensions

Safe

- A named clinician for each young person must be identified who will take on care for people being transferred to adult services.

Accessible

- The paediatric respiratory team should be able to identify all children known to paediatric respiratory services in secondary or tertiary care approaching the age to transfer to adult services, so that they can alert the adult respiratory team and agree a schedule for information transfer.
- It is recommended that all young people with CF should attend a transitional clinic from age 15. The vast majority of young people with chronic respiratory disease should have their care fully transferred to adult services by age 18, although psychosocial maturity should be taken into account. For some young people who are approaching end of life it is appropriate for them to remain with the paediatric team for a longer period.

Effective

- All HSC Trusts should have an appropriate referral pathway for smooth and co-ordinated transition for adolescents with chronic respiratory disease including difficult asthma, OSAS, cystic fibrosis, bronchiectasis and those receiving LTV.

Person Centred

- It is important that young people with respiratory conditions and their parents/carers (where appropriate) are involved in decision making with regard to transitional care, and receive adequate written and verbal information to ensure they are aware of ongoing arrangements of care. Consideration must also be given to the psychosocial maturity of young people when deciding when transitional care is appropriate, within broad age limits.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Trust self-assessment against service specifications for transitional care arrangements: *i) Difficult asthma* *ii) Cystic fibrosis* *iii) Bronchiectasis* *iv) LTV* *v) OSAS*	Trusts reports and RBHSC report	All trusts should be able to meet service specifications	March 17

7.3 ACUTE OXYGEN THERAPY

In acutely ill people and those admitted to hospital requiring emergency oxygen therapy, acute oxygen therapy should be prescribed to achieve normal or nearly normal levels of oxygen in the blood. This does not apply however, to some people with respiratory failure who have high levels of carbon dioxide in the blood, as administration of oxygen can be dangerous.

Overarching Standard 49 – Acute Oxygen Therapy

All acutely ill people, apart from those at risk from hypercapnic respiratory failure, should have oxygen prescribed to achieve a normal or near normal oxygen saturation.

Rationale:

There are hazards associated with both the overuse and underuse of oxygen therapy. These can be avoided by having safe processes for prescribing and monitoring oxygen therapy.

References:

British Thoracic Society (BTS) (2008) Guideline for emergency oxygen use in adult patients
http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Emergency%20Oxygen/Emergency%20oxygen%20guideline/EmergencyOxygenSupplement_web.pdf

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Integrated Care Partnerships (ICPs)
Primary Care

Quality Dimension

Safe

- Oxygen saturation should be measured in hospital in all people who are breathless or critically ill.
- Supplemental oxygen should be given to all these people who are hypoxaemic except from those at risk from hypercapnic respiratory failure.
- All oxygen use should be recorded on standard oxygen prescription document or designated oxygen section on all drug prescribing cards.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Emergency oxygen therapy should be prescribed using a target saturation range for people admitted to hospital requiring oxygen therapy.	BTS Emergency Oxygen Audit	60% 80%	March 16 March 17

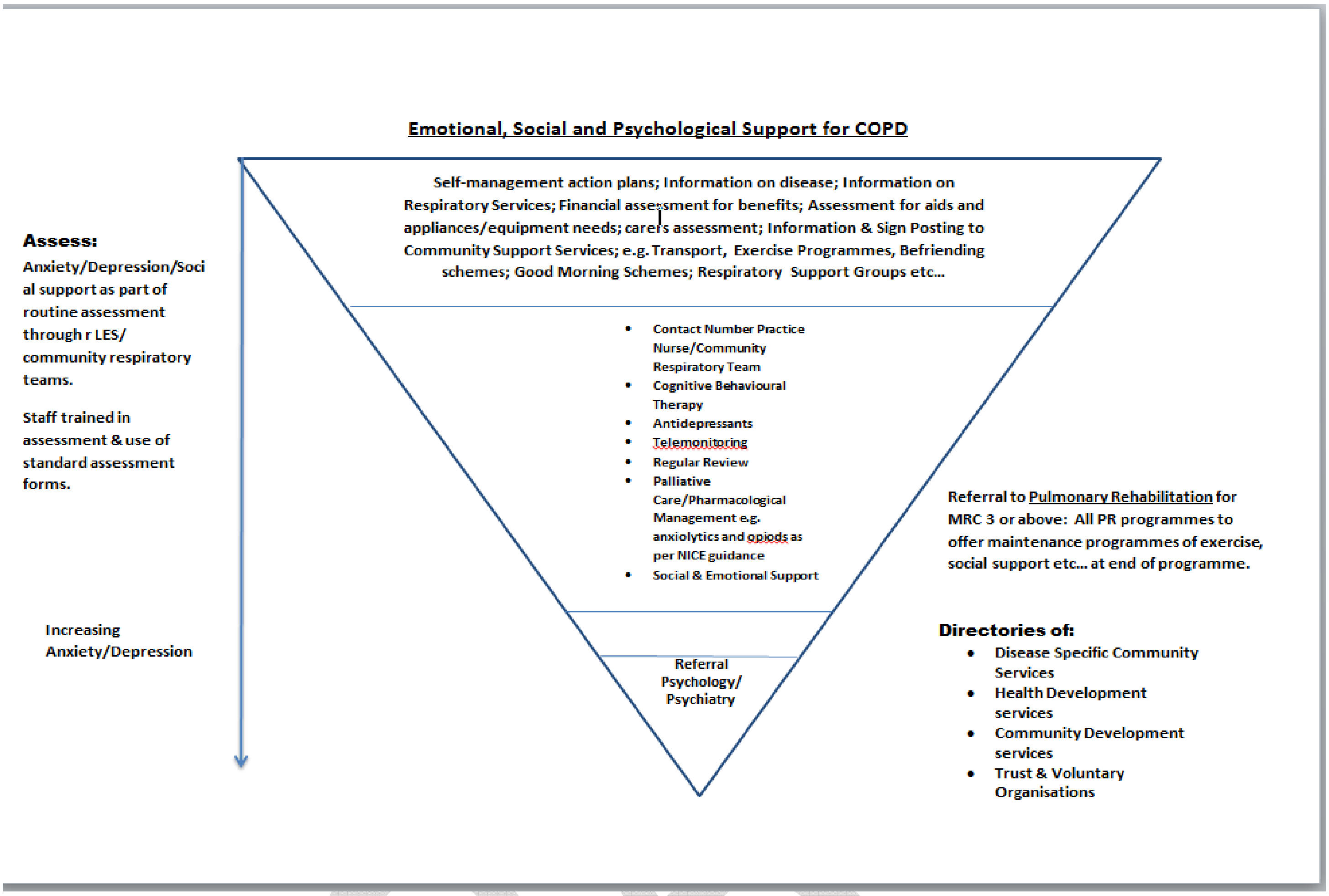
7.4 SOCIAL AND EMOTIONAL SUPPORT

Access to social and emotional support is an essential part of care for people with chronic conditions such as severe respiratory disease. This support helps to reduce the effects of the illness on the health and wellbeing of people with the illness, their relatives and carers: and should be provided as well as on-going medical treatment.

Chronic disability often means that people and their carers are isolated from both formal (e.g. work) and informal (e.g. friends, involvement in community life) social networks over time. Where social networks are broken, this has a very negative impact on the health and wellbeing of those concerned.

The social and emotional support standards seek to ensure that health and social care staff are proactive in assisting individuals and their carers affected by severe respiratory conditions to maintain and develop strong social networks appropriate to their own circumstances.

The standards also seek to ensure that health and social care staff have the appropriate training to detect mental well-being problems such as anxiety and depression which are associated with more severe chronic conditions; and to be able to deal with these appropriately. This may require additional support such as referral to a GP for therapies such as antidepressants or cognitive behavioural therapy. In more severe mental health problems referral may be required to psychology or psychiatry. The model for the management of Emotional, Social and Psychological Support for Respiratory Disease shows appropriate tiers of interventions required.



Emotional, Social and Psychological Support for COPD

Self-management action plans; Information on disease; Information on Respiratory Services; Financial assessment for benefits; Assessment for aids and appliances/equipment needs; carers assessment; Information & Sign Posting to Community Support Services; e.g. Transport, Exercise Programmes, Befriending schemes; Good Morning Schemes; Respiratory Support Groups etc...

- Contact Number Practice Nurse/Community Respiratory Team
- Cognitive Behavioural Therapy
- Antidepressants
- Telemonitoring
- Regular Review
- Palliative Care/Pharmacological Management e.g. anxiolytics and opiods as per NICE guidance
- Social & Emotional Support

Referral Psychology/ Psychiatry

Assess: Anxiety/Depression/Social support as part of routine assessment through r LES/ community respiratory teams.

Staff trained in assessment & use of standard assessment forms.

Increasing Anxiety/Depression

Referral to Pulmonary Rehabilitation for MRC 3 or above: All PR programmes to offer maintenance programmes of exercise, social support etc... at end of programme.

Directories of:
- Disease Specific Community Services
- Health Development services
- Community Development services
- Trust & Voluntary Organisations

The quality dimensions and related performance indicators seek to ensure that:

- Specialist community respiratory team members receive appropriate training and support to enable them to identify and effectively deal with the emotional and social support dimensions of the care of individuals and carers affected by severe respiratory disease;
- Self-help and self-management and exercise support groups are amongst the menu of support options widely available to individuals and carers affected by respiratory disease; and,
- Family/carers are supported

The aim of the standard is to reduce the overall impact of respiratory disease on the person and their family.

Overarching Standard 50 – Social and emotional support
All people with severe respiratory disease and their carers should be offered an holistic assessment of their needs and be facilitated and supported to maintain their connections with social networks and community life, in order to promote wellbeing and mitigate the potentially isolating effects of long term disability.

Rationale:
Long term conditions have the potential over time to isolate patients/clients and their carers from regular access to social networks and leisure and exercise opportunities. The importance of this access is now well recognised for the maintenance of health and wellbeing. It is therefore essential that the specialist respiratory multidisciplinary team includes these dimensions in their protocols for the assessment of need and provision of treatment and support, and develops increased capability to do so effectively.

Evidence:
Living With Long Term Conditions: A Policy Framework (DHSSPSNI, April 2012)
http://www.dhsspsni.gov.uk/long-term-condition

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (DHSSPSNI, December 2011)
www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts (in collaboration/partnership with Voluntary & Community Sectors)
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimension

Patient Centred
- Self-help groups should be established and facilitated in each locality.
- The Expert Patient Programme (EPP) should be made available to all those with respiratory disease. These are generic programmes suitable for people with any type of chronic disease to enable them to deal with having a long term condition and participate fully in society.
- The members of the specialist community respiratory team should be trained (in the use of the community development approach) and link collaboratively with local health and community development staff to develop a holistic approach to patient management.
- The members of the specialist respiratory team should be trained in the

detection and management options for anxiety and depression associated with chronic disease.

- All carers should be offered assessment and support as appropriate.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of local areas with patient self-help support groups supported and facilitated by HSC Trusts (approximately 80,000 population).	HSC Trust / ICP report	100%	March 18
Percentage of local areas with generic expert patient programmes available for those with respiratory disease (approximately 80,000 population).	HSC Trust / ICP report	100%	March 18
Percentage of people on specialist community respiratory team caseloads who have had an holistic assessment and action planning of their social and emotional support needs.	HSC Trust / ICP report	80%	March 18
Percentage of local LCG areas with timely access to psychology services for those with severe anxiety and depression secondary to respiratory disease when other interventions are not sufficient, as per the emotional social and psychological support model.	HSC Trust / ICP report	100%	March 18
Percentage of people who have been offered to move on from pulmonary rehabilitation to local exercise/support groups.	HSC Trust / ICP report	80%	March 18
Percentage of carers (of people with respiratory disease who are on community team caseloads) who	HSC Trust / ICP report	90%	March 18

have been offered a formal carers assessment, where appropriate.			

7.5 INFORMATION

Access to high quality, up to date, information is critical to empower individuals, families and carers affected by respiratory conditions to be fully involved in decisions about prevention, self-care, treatment options, care and long term support. The information standard, and associated quality dimensions and performance indicators, seeks to ensure basic information is available to individuals and carers affected by respiratory disease, irrespective of where they live. This information should be available on the condition, self-care, secondary prevention, treatment, care and on-going support options, and how to access them. Health and social care professionals should be proactive in helping those affected by respiratory disease to access this information.

Overarching Standard 51 – Information

All patients, clients and carers should receive information which will allow them to know about general management options for their condition as well as the range of services available locally, including health promotion and appropriate community support services.

Rationale:

Well informed self-care is critical to maximising the quality of life experienced by individuals who have a respiratory disease, and their carers; and reducing the impact of illness on overall health and wellbeing.

Evidence:

Living With Long Term Conditions: A Policy Framework (DHSSPSNI, April 2012) http://www.dhsspsni.gov.uk/long-term-condition

Transforming Your Care: A Review of Health and Social Care in Northern Ireland (DHSSPSNI, December 2011) www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

Guidance for HSC organisations on arrangements for implementing effective personal and public involvement in the HSC. Circular Reference, September 2012. Safety, Quality & Standards Directorate, DHSSPSNI. http://www.dhsspsni.gov.uk/index/phealth/sqs/sqsd-circulars/sqsd-circulars-2011-2012.htm

Guidance on strengthening Personal and Public Involvement in Health and Social Care (DHSSPS, 2007) http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

Good Medical Practice (GMC, 2006) http://www.gmc-uk.org/guidance/good_medical_practice/index.asp

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order (2003) http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

The Quality Standards for Health and Social Care Supporting Good Governance and Best Practice in the HPSS (March 2006) http://www.dhsspsni.gov.uk/spsd-standards-quality-standards

Community Development Performance Management Framework. (Community Development Managers Regional Group). Supported by the Community Development and Health Network (2007)

Carers and Direct Payments (Northern Ireland) Act (2002)
http://www.opsi.gov.uk/legislation/northernireland/acts/acts2002/nia_20020006_en_1

DHSSPS (2007) Caring for Carers. Recognising, Valuing and Supporting the Caring Role http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

DHSSPS (2005) Primary Care Strategic Framework - Caring for People Beyond Tomorrow http://www.dhsspsni.gov.uk/show_publications?txtid=14302

DHSSPS (2005) Regional Strategy – A Healthier Future- A Twenty Year Vision for Health and Wellbeing in Northern Ireland, 2005-2025
http://www.dhsspsni.gov.uk/show_publications?txtid=7282

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts (in collaboration and partnership with voluntary organisations).
Primary Care (including community pharmacy)

Quality Dimension

Patient Centred

- Information should be made available in a variety of suitable formats including written, web based, face to face, on what to expect by way of possible treatments (pathways where appropriate), types of services and carer support available locally, regionally and nationally.
- Information should be made readily available, in a variety of formats, on how to access benefits and local transport/travel schemes.
- Information should be made readily available, in a variety of formats, on local physical activity schemes, healthwise schemes, smoking cessation schemes and weight management programmes.
- Information should be made available on the details of local self-support groups, expert patient programmes and available local community support resources such as befriending schemes, older people's groups, healthy living centres.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of local* areas where directories of services are available in a variety of formats written (*Approximately 150,000 population).	HSC Trust ICP report	All areas	March 17
Information available (including links to above) on HSCB and NI Direct websites	HSCB	All websites	March 17
Percentage of people with respiratory disease accessing online support groups via HSC web and portal.	HSCB report	Baseline to be established	March 16
		10% increase	March 17
		20% increase	March 18
Percentage of carers of people with respiratory disease accessing online support groups via HSC web and portal.	HSCB report	Baseline to be established	March 16
		10% increase	March 17
		20% increase	March 18

7.6 TRAINING

Overarching standard 52 – Training
All HSC staff, as relevant, should be appropriately trained to meet modern authoritative standards, and have the necessary knowledge, skills and competencies to provide respiratory services and manage respiratory conditions.

Rationale:
In order to make the best use of resources it is important to have the right people with the right skills working in the right place (DHSSPS Transforming Your Care 2011). Objective 3 of Quality 2020 states 'We will provide the right education, training and support to deliver high quality service' (DHSSPS 2011)

HSC professionals can identify learning and development needs using recognised competency assessment tools. The Respiratory Competency Assessment Tool (NIPEC 2008, 2012) enables nurses to assess competencies in the areas of COPD and asthma.

Spirometry is a necessary investigation for diagnosis and severity assessment in people with COPD and other respiratory conditions, however over 25% of people with COPD have been wrongly diagnosed and this is usually associated with poorly performed spirometry. The Regional Respiratory Forum has set the standards for spirometry training in Northern Ireland.

All HSC professionals working with individuals with respiratory conditions should receive Brief Intervention Training for smoking cessation. This training should be in keeping with the Regional Training Framework for Smoking Cessation.

Evidence:
Training Framework for Smoking Cessation Services in Northern Ireland. Department of Health, Social Services and Public Safety, Northern Ireland (DHSSPNI) April 2003 http://www.dhsspsni.gov.uk/smoking_cessation.pdf

CG101 Chronic obstructive pulmonary disease (update): NICE guideline – 2010 http://guidance.nice.org.uk/CG101

British Thoracic Society / Scottish Intercollegiate Guidelines Network Guidelines on Management of Asthma [this is a 'Living Guideline' i.e. is updated annually http://www.brit-thoracic.org.uk/ClinicalInformation/Asthma/AsthmaGuidelines/tabid/83/Default.aspx

DHSSPS (2011) *Quality 2020 A 10-Year Strategy to Protect and Improve Quality in Health and Social Care in Northern Ireland.* Belfast, DHSSPS

Department of Health (2012) *An Outcomes Strategy for COPD and Asthma.* London. DoH

Northern Ireland Practice and Education Council (NIPEC) (2008) *Learning and Development Strategy for Asthma and Chronic Obstructive Pulmonary Disease Care and Management (Nursing) with Supporting Competency Framework: Final Report.* Belfast, NIPEC

Northern Ireland Practice and Education Council (NIPEC) 2012) *Respiratory Competency Assessment Tool (R-CAT) 2012 Review Document*. Belfast. NIPEC

Primary Care Commissioning (PCC) (2013) *A Guide to Performing Quality Assured Diagnostic Spirometry.* PCC

RCGP General Practice Foundation (2012) *General Practice Nurse Competencies*. London RCGP

Respiratory Forum (2012) *Spirometry Training Guidance*. Belfast. PHA

Health and Social Care Board (HSCB) (2011) *Transforming Your Care: A review of Health and Social Care in Northern Ireland*. Belfast, HSCB

Responsibility for delivery / implementation:

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Integrated Care Partnerships (ICPs)

Quality Dimensions

Safe
All HSC professionals performing and interpreting spirometry should have undergone appropriate training in line with regional best practice guidance.

Accessible
All HSC professionals involved in the care of people with COPD and other respiratory conditions should have timely access to spirometry and be competent in the interpretation of the results to ensure accurate diagnosis and treatment.

Effective
All HSC professionals need to be appropriately trained on inhaler technique, as inhalers should be prescribed only after patients have received training in the use of the device and have demonstrated satisfactory technique.

Efficient
Investing in evidence based training for multidisciplinary health care staff promotes high quality care and ensures health care workers are equipped to diagnose respiratory conditions accurately, manage people with these conditions effectively and provide support for addressing lifestyle factors such as smoking. This can contribute to improved health outcomes and quality of life, as well as a reduction in morbidity and unplanned admissions.

Equitable
All people should be offered early smoking cessation intervention by HSC professional who are appropriately trained.

Person Centred
All HSC professionals should be appropriately trained in use of self-management plans for those diagnosed with COPD and Asthma.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of GP employed nurses who have completed self-assessment as per NIPEC R-CAT.	ICPs	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of Trust employed specialist paediatric respiratory nurses who have completed self-assessment as per NIPEC R-CAT.	Trusts	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of Trust employed specialist adult respiratory nurses who have completed self-assessment as per NIPEC R-CAT.	Trusts	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage (%) of Trust-employed specialist respiratory physiotherapists, carrying out pulmonary rehabilitation, who have been trained to the standards agreed by the regional respiratory forum.	Trusts	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of GP practices who have a minimum of 1 registered nurse who has successfully completed a recognised post-graduate respiratory course in COPD, level to be agreed by the GMS training group.	ICPs	Baseline to be established Performance levels to be determined	March 16 March 17 March 18

Percentage of GP practices who have a minimum of 1 registered nurse who has successfully completed an approved post-graduate respiratory course in asthma, level to be agreed by the GMS training group.	ICPs	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of GP practices who have a minimum of 1 registered nurse who has completed an approved spirometry training course*. **An approved spirometry course should cover theoretical aspects as well as practical aspects, and individuals should be trained to both conduct the test as well as interpreting the result.*	ICPs	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of GP practices where a primary care HSC professional has completed brief intervention training for smoking cessation.	ICPs	Baseline to be established Performance levels to be determined	March 16 March 17 March 18
Percentage of Trust HSC professionals providing a respiratory service who have completed brief intervention training for smoking cessation.	Trust's monitoring returns to PHA	Baseline to be established Performance levels to be determined	March 16 March 17 March 18

7.7 Medicines Management

Prescribing is a common medical intervention experienced by people with respiratory disease and the concurrent use of multiple medicines to prevent disease is common. A high proportion of preventable hospital admissions are due to common respiratory conditions. It is important to have good medicines management systems in place across all healthcare settings to ensure that people receive the right medicines at the right dose in the right form at the right time.

Respiratory medicines are expensive and account for 10% of the total prescribing budget in NI. Medicines prescribed in accordance with local national guidelines offer assurance of high quality care and maximum health gains from medicines. As people age, their use of medicines increases due to the development of long-term medical conditions and more preventative medicines are prescribed. When used appropriately, medicines can improve both functioning and quality of life.

Research shows that around 50% of medicines for long-term conditions are not taken as prescribed and that peoples' beliefs and preferences about medicines are the most important factor in how they use them. In order to encourage adherence to prescribed medicines, people and their carers should be given advice and information about their medicines and have an opportunity to participate in informed decision making about their treatment.

Compiling and keeping accurate records of medicines taken reduces the risk of errors especially when people are transferring from one care setting to another. Regular review of all medicines being taken ensures that all medicines remain appropriate, safe and effective in the longer term and minimises waste.

The Framework includes two standards relating to medicines management:

1. Medicines Management. In partnership with healthcare professionals, all people with respiratory disease should be provided with appropriate, safe and effective medicines and medicines information to enable them to gain maximum benefits from medicines to maintain or increase their quality and duration of life.

2. Medicines Review. People with respiratory disease should have a systematic review of all their medicines at appropriate intervals along the care pathway to ensure that their medicines continue to be appropriate, and that they participate in the treatment as prescribed.

Overarching Standard 53 – Medicines Management

In partnership with healthcare professionals, all people with respiratory disease should be provided with appropriate, safe and effective medicines and medicines information to enable them to gain maximum benefits from medicines to maintain or increase their quality and duration of life.

Rationale:

Medicines management processes for people should ensure that the right person receives the right medicine at the right dose in the right formulation at the right time. People should be provided with medicine that is prescribed responsibly in accordance with local and national guidelines offering assurance of high quality care.

Good documentation of prescribing decisions, recording of reported side effects and an assessment of whether medicine has been effective is necessary to ensure safe and effective care and minimise waste.

All prescribers should work with the support and advice of appropriately trained pharmacists. They should provide support and information for people taking medicines through a partnership approach where an informed dialogue takes place about the choice of medicine. This enables people to make an informed decision about their medicine and encourages adherence to the agreed treatment plan. Health and social care professionals should ensure that their instructions have been fully understood.

Evidence:

Blunt I. (2013) Focus on Preventable admissions: Trends in Emergency Admissions for ambulatory care sensitive conditions 2001-2013. Nuffield Trust. http://www.nuffieldtrust.org.uk/publications/focus-preventable-admissions

Business Services Organisation (2013) Prescribing database, Health & Social Care Northern Ireland.

Department of Health (2005) The National Service Framework for Long Term Conditions. www.dh.gov.uk

Pharmaceutical Society of Australia (2010) Professional Practice Standards. Version 4. www.psa.org.au

Sabate E. (2003) Adherence to long-term therapies: Evidence for action. Switzerland: World Health Organization.

Stevenson F. The patient's perspective. (2004) In: Bond C, editor. Concordance, a partnership in medicine taking. Pharmaceutical Press.

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
Health and Social Care Trusts
Primary Care (including Local Commissioning Groups, Integrated Care Partnerships, General Practitioners, Community Pharmacists)

Quality Dimensions

Safe

- The right medicine at the right dose in the right formulation at the right time for the individual minimises the risk of adverse side effects.
- There should be clear responsibility for medicines management. Properly managed, prescribed medication can improve quality of life.

Accessible

- Timely access to appropriate treatment promotes recovery.

Effective

- Prescribing decisions should be evidence-based. Medicines should be prescribed, administered and monitored in accordance with local and national guidelines and the NI medicines formulary.

Person Centred

- The provision of medicines should be based on what is important to people as individuals, what has worked in the past and what hasn't worked for them. People and their carers should be active partners in decisions about medicine prescribed for them. Individual prescribing decisions must be recorded.

Performance indicator:	**Data Source**	**Anticipated Performance level**	**Date to be achieved by**
Percentage of respiratory prescribing in accordance with local medicines formulary.	HSC Trusts Business Services Organisation's prescribing database	70% On-going in tandem with development of the NI formulary	March 16 March 17 March 18
Percentage of people with respiratory conditions accessing a medicines management support service.	HSCB (community pharmacy contract) Trusts (self-administration of medicines)	Baseline to be established Performance levels to be determined	March 16

Overarching Standard 54 – Medicines Review

People with respiratory disease should have a systematic review of all their medicines at appropriate intervals along the care pathway to ensure that their medicines continue to be appropriate, and that they participate in the treatment as prescribed.

Rationale:

Respiratory disease is associated with the use of multiple medicines. This may cause problems through drug interactions. There may also be instances where appropriate medicines are under-used. People with respiratory disease and older people are often those at highest risk of significant morbidity or mortality and are most likely to benefit from preventative medicines; however there is a risk of adverse drug events. Regular medicines review ensures that people receive appropriate medicines and minimises medicines waste.

When people move across care settings there is a risk of medicines-related errors due to inaccuracies in the medicines list. It is essential that every time a person moves to another care setting, accurate and reliable information about their medicines is transferred at the same time. Errors in taking medicines are an important cause of admission to hospital. Records of medicines are kept in a range of formats in a variety of settings and are not easily shared. Therefore, any individual record will only be as accurate as the last update and may not reflect all the medicines that a person is taking. A medicines review is best performed once an accurate list of medicines has been compiled from a number of sources.

Medicines reviews vary in complexity ranging from an opportunistic discussion with a healthcare professional to a more comprehensive and proactive approach by the prescriber. Different approaches are taken in practice for different purposes. Prescribers conducting face to face clinical medicine reviews with individuals should include all medicines prescribed or bought over the counter, seek the person's (or their carer's) consent to any changes made and aim to achieve concordance about medicines-taking. The outcome of the review should be documented in the person's records and the impact of any changes should be monitored. Information on the medication review should be shared with the appropriate healthcare professionals so that medication records are updated.

Evidence:

Clyne W, Blenkinsopp A, Seal R. (2008) National Prescribing Centre. A guide to medication review. Liverpool: National Prescribing Centre. www.npc.co.uk

National Collaborative Medicines Management Services Programme (2002)

Briefing: Room for Review. A Summary Guide To Medication Review: The Agenda For Patients, Practitioners And Managers. Task Force On Medicines Partnership. www.npc.nhs.uk

Institute for Healthcare Improvement (2011) Innovation at Its Best: Medication Reconciliation.www.ihi.org

National Prescribing Centre (2008) Medicines Reconciliation: a guide to implementation. www.npc.nhs.uk

Pharmaceutical Society of Australia (2010) Professional Practice Standards. Version 4. www.psa.org.au

Responsibility for delivery / implementation

Health and Social Care Board
Public Health Agency
Health and Social Care Trusts
Primary Care (including Local Commissioning Groups, Integrated Care Partnerships, General Practitioners, Community Pharmacists)

Quality Dimensions

Safe

- The right medicine for an individual improves their health outcome, reduces adverse effects and reduces unwanted and unused medicine.
- The integration of medicines management services and improved communication and sharing medication records between care settings minimises the risk of transcription errors.

Accessible

- Prescription of the right medicine at the right time improves the current and future management of their medical condition.

Effective

- Medicines review has numerous potential benefits for people including improving the current and future management of their medical condition, improving health outcomes through optimal medication, reduction in adverse effects and reduction in unwanted or unused medicines.

Person Centred

- People should be active partners in decisions about medicine prescribed for them.

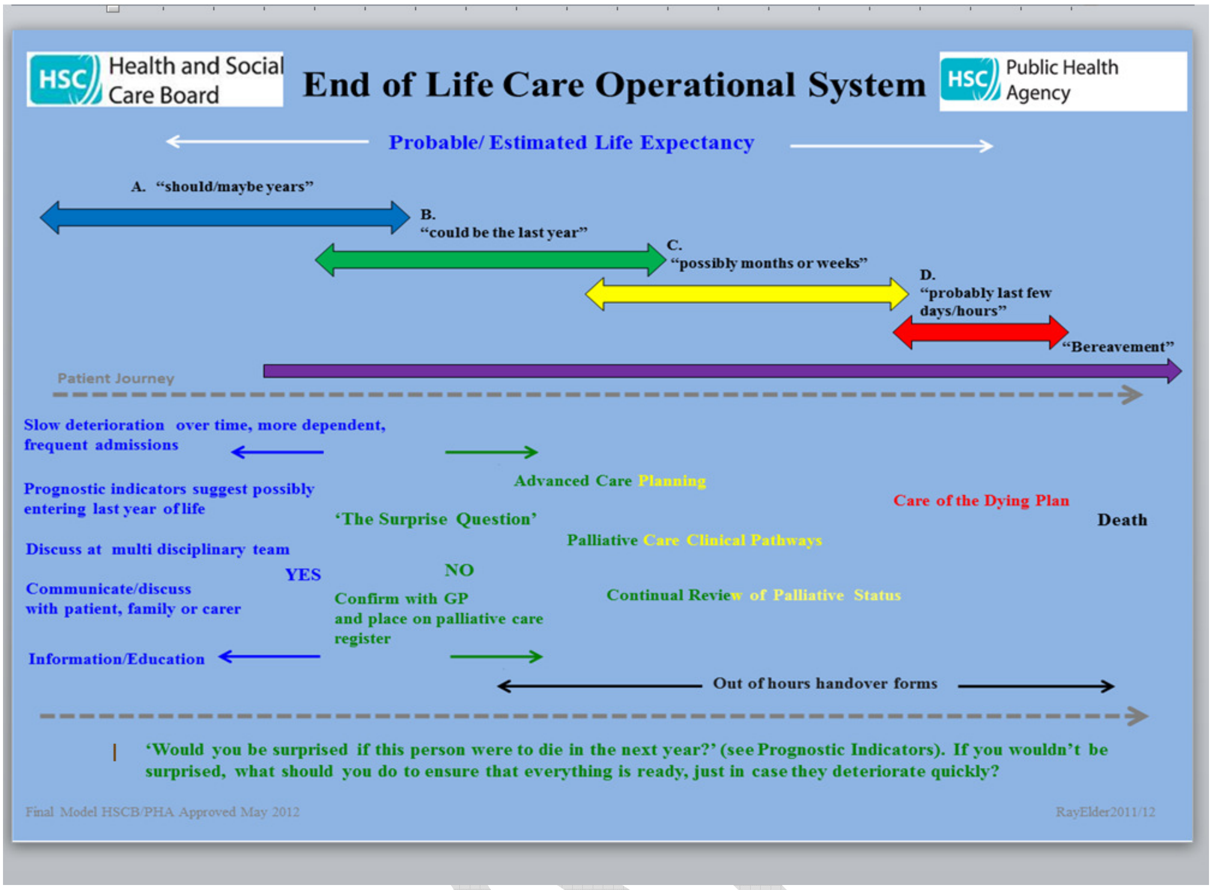
Performance indicator:	**Data Source**	**Anticipated Performance level**	**Date to be achieved by**
Percentage of people with respiratory disease in secondary care who have had their medicines list checked and verified as accurate on admission.	HSC Trusts Audit	Baseline to be established Performance levels to be determined	March 17

8. STANDARDS FOR PALLIATIVE AND END OF LIFE

Palliative Care is defined as: “the active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments”. More latterly the importance of “early identification and impeccable assessment” have been added to this definition as it is thought that problems at the end of life can have their origins at an earlier time in the progression of the illness and should therefore be recognised and dealt with sooner.

Palliative Care has traditionally been used for people mainly with a cancer diagnosis. However services for those with non-malignant conditions have not been equally developed across Northern Ireland. It is also estimated that two thirds of all people who die in Northern Ireland per year (about 9,600) would benefit from palliative care, but do not receive it. This approach is appropriate for those with chronic conditions such as respiratory disease, heart failure, neurological, renal and other degenerative conditions like dementia and those elderly people approaching end of life.

End of Life Care is an integral part of the wider concept of palliative care and consequently many of the same principles apply. It can be described as that time where an individual’s condition has deteriorated to the point where death is possible or would not be an unexpected event within the next year. This time scale can be uncertain in many conditions and it is important that acute life-saving treatment is not withheld from someone who could benefit from it. An End of Life Care Operational System has been developed which supports the use of a combined palliative and acute treatment approach where the person could possibly be in the last year of life, until it possible to identify definitively the last few months/weeks at the end of life, when the main approach will then be a palliative care one. It is recognised that it may not be possible to definitively identify the last phase of life but the use of this approach will improve quality of life until death.


Health and Social Care Board

End of Life Care Operational System

Public Health Agency

Probable/ Estimated Life Expectancy

A. "should/maybe years"

B. "could be the last year"

C. "possibly months or weeks"

D. "probably last few days/hours"

"Bereavement"

Patient Journey

Slow deterioration over time, more dependent, frequent admissions

Prognostic indicators suggest possibly entering last year of life

Discuss at multi disciplinary team

YES

Communicate/discuss with patient, family or carer

Information/Education

'The Surprise Question'

NO

Confirm with GP and place on palliative care register

Advanced Care Planning

Palliative Care Clinical Pathways

Continual Review of Palliative Status

Care of the Dying Plan

Death

Out of hours handover forms

'Would you be surprised if this person were to die in the next year?' (see Prognostic Indicators). If you wouldn't be surprised, what should you do to ensure that everything is ready, just in case they deteriorate quickly?

Final Model HSCB/PHA Approved May 2012

RayElder2011/12

Identification of possible last year of life

Deterioration of a patient's condition should be identified according to the 3 triggers of the Gold Standard Framework prognostic indicator guide for adults with advanced disease.

Identification of this stage of the patient's illness should be carried out in full collaboration between patient, carers, the patient's GP and secondary care consultant and their respiratory specialist nurse who is usually the ongoing key worker until the last few weeks of life. One important role of the key worker is to ensure timely communication between all professionals and carers involved.

For assessment to decide if the patient may have Supportive/Palliative Care needs– to identify these patients there are a number of trigger questions:

- **The surprise question**

'Would you be surprised if this patient were to die in the next 6-12 months' – an intuitive question integrating co-morbidity, social and other factors.

- **Choice/Need**

The patient with advanced disease makes a choice for comfort care only, not ‘curative’ treatment, or is in special need of supportive /palliative care.

- **Clinical indicators**

Specific indicators of advanced disease e.g. for COPD:

- Disease assessed to be severe e.g. FEV1 < 30% predicted
- Recurrent hospital admissions (> 3 in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy criteria
- MRC breathlessness grade 4/5
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous ICU/NIV/resistant organism

Preferred place of care

Most people would prefer to die at home (including residential and nursing home where this is the person’s usual home) where this is possible. Advance care planning allows more informed choice of care for people with respiratory disease. It means that all professionals involved with the person and family will know their preferences and be able to plan and support the person according to their wishes if this is possible. An advanced care plan is not legally binding.

Education and training and support of professionals

All health and social care professionals who are caring for those people with respiratory disease who have palliative and end of life care needs should have appropriate skills in communication, advance care planning and expertise in the management of pain and other symptoms and provision of psychological, social and spiritual support. The work of specialist palliative care teams is vitally important in training and education of respiratory care staff, support in the management of people with respiratory disease and management of complex symptoms.

Overarching standard 55: Palliative and End of Life Care

All people with advanced progressive incurable respiratory conditions should have their end of life care needs identified; co-ordinated care provided by a designated key worker, to meet these needs; and supported to die in their preferred place of care, in close collaboration with family and carers at all stages.

Rationale:

Early identification of palliative and end of life care needs of patients, their family and carers maximises quality of life for all in terms of physical, emotional, social, financial, and spiritual health and wellbeing.

Professionals should have the skills and knowledge to discuss end of life issues honestly and sensitively. Earlier identification allows symptoms to be controlled and comfort maximised. This allows quality of life until death and supports family and carers through bereavement.

Co-ordination of care is important to support well-being and every person identified as possible last year of life should have a named key worker (usually a specialist community respiratory nurse specialist who links particularly with other community nurses such as district nursing) to co-ordinate care.

Advance care planning allows more informed choice of care and enables people to be more supported to die in their preferred place of care.

Evidence:

- Living matters, Dying Matters. A Palliative and End of Life Care Strategy for Adults in Northern Ireland, March 2010. http://www.dhsspsni.gov.uk/8555_palliative_final.pdf
- National Institute for Health and Clinical Excellence (NICE) Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care (2010) http://www.nice.org.uk/Guidance/CG12
- National Institute for Health and Clinical Excellence (NICE) Chronic Obstructive Pulmonary Disease; Quality Standards (2011) http://guidance.nice.org.uk/qualitystandards/qualitystandards.jsp
- Gold Standards Prognostic Framework Programme, NHS End of Life Care programme (2006) Prognostic Indicator Paper vs 2.25 http://www.goldstandardsframework.nhs.uk
- National Institute for Health and Clinical Excellence (NICE) (CG 163, June 2013) Diagnosis and management of suspected idiopathic pulmonary fibrosis.

http://publications.nice.org.uk/idiopathic-pulmonary-fibrosis-cg163

- British Thoracic Society Interstitial Lung Disease Guideline Group. Interstitial lung disease guideline. Thorax 2008; 63 (Suppl V):v1-v58. http://www.brit-thoracic.org.uk/portals/0/guidelines/dpldguidelines/thorax%20sept%2008.pdf

Responsibility for delivery / implementation

HSC Board
Public Health Agency
HSC Trusts
Primary Care (including community pharmacy)
Voluntary Palliative Care Organisations
Private nursing home and care providers
Integrated Care Partnerships (ICPs)

Quality Dimension
Equitable • Patients and family/carers should have access to a range of services including 24-hour nursing (with rapid response), AHP input, night sitting, day sitting, social care, care packages, pharmacy, hospice-at-home, intermediate care/respite/daycare, dedicated specialist in-patient beds, specialist palliative care advice and bereavement services. **Patient Centred** • Deterioration of a patient’s condition should be identified according to the 3 triggers of the Gold Standard Framework prognostic indicator guide for adults with advanced disease and in collaboration between patient, carers, the patient’s GP, secondary care consultant and their specialist nurse (COPD) and appropriate indicators of possible last year of life in Idiopathic Pulmonary Fibrosis . • Co-ordination of care is essential and all people should have a named key worker to co-ordinate care in the possible last year of life. • All patients and family/carers should have an agreed plan of care which ensures timely and effective communication of information, reflecting their individual care needs including intended outcomes of care. • Advance care planning should include Do Not Attempt Resuscitation (DNAR) decision making and Preferred Place of Care in the event of deterioration to include hospitalisation, Non-invasive Ventilation (NIV) and Intensive Care, where appropriate. • There should be effective communication between staff caring (GP/consultant and key worker) for people with end stage respiratory disease about stage of illness, and this should be communicated with the person (if appropriate) and their family/carers. • Patients should be enabled to die in their preferred place of care, where possible.

Performance Indicator:	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people on community specialist team caseloads who have been assessed as to whether they have palliative care needs using Northern Ireland palliative care guidance (for COPD) or appropriate indicators of possible last year of life in Idiopathic Pulmonary Fibrosis.	Community team audit	50% 90%	March 16 March 18
Percentage of people identified as being possibly in last year of life on community team caseloads who are recorded on the GP palliative care register and discussed at the practice multi-disciplinary meeting.	Trust report	50% 90%	March 16 March 18
Percentage of people with a respiratory diagnosis on the Trust palliative care database who have had an holistic assessment and a care plan developed (including carer needs).	Trust palliative care database	50% 90%	March 16 March 18
Percentage of people with respiratory diagnosis on the Trust palliative care database with an identified named key worker (usually specialist respiratory team member coordinating with district nursing who then takes on key worker role in last few weeks) responsible for ensuring the 24 hour plan of care is communicated to relevant professionals.	Trust palliative care database	50% 90%	March 16 March 18

Percentage of people with respiratory disease on the Trust palliative care database who are enabled to die in their appropriate preferred place of care (identified as part of regularly reviewed assessments).	Trust palliative care database	10% 30%	March 16 March 18
Percentage of the specialist respiratory team members who have had training in appropriate palliative care competencies.	Trust report	80% 90%	March 16 March 18
Percentage of specialist respiratory team members trained in appropriate communication skills.	Trust report	95%	March 16

Overarching standard 56 – Palliative and End of Life Care* (Generic)
All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care.

Rationale:
Most people would prefer to die at home (including residential and nursing home where this is the person's usual home) where this is possible.

In order to support this, identification of the possible last year/months/weeks of life should take place. Evidence shows that when end of life care needs are identified there is improved quality of life and even prolonged life, compared to when this stage of illness is not identified, particular in non-cancer conditions.

Advanced care planning allows more informed choice of care and enables people to be more supported to die in their preferred place of care.

*Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (WHO, 2002)

*End of life care refers to the possible last year of life. It helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. At this stage however it is often still appropriate to provide acute treatment in conjunction with palliative care, particularly in long term conditions. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care, Focus on Commissioning, Feb 2007).

Evidence:
Living matters, Dying Matters. A Palliative and End of Life Care Strategy for Adults in Northern Ireland, March 2010.
http://www.dhsspsni.gov.uk/8555_palliative_final.pdf

National Institute for Health and Clinical Excellence (NICE) Improving Supportive and Palliative Care for Adults with Cancer (2004)
http://www.nice.org.uk/Guidance/CSGSP

Supportive and Palliative Care for Advanced Heart Failure, Coronary Heart Disease Collaborative, NHS Modernisation Agency (2004) http://www.library.nhs.uk/cardiovascular/ViewResource.aspx?resID=78319

NICE Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care (2003) http://www.nice.org.uk/Guidance/CG5

NICE Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care (2010) http://www.nice.org.uk/Guidance/CG12

NICE Chronic Obstructive Pulmonary Disease; Quality Standards (2011) http://guidance.nice.org.uk/qualitystandards/qualitystandards.jsp

Regional Cancer Framework: A Cancer Control Programme for Northern Ireland DHSSPSNI (2006) http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

NICE Cancer Service Guidance (CSGSP): Improving supportive and palliative care for patients with cancer, March 2004 http://www.nice.org.uk/Guidance/CSGSP

Definitions of levels of palliative care, National Council for Palliative Care http://www.ncpc.org.uk/site/professionals/explained

Gold Standards Prognostic Framework Programme, NHS End of Life Care programme (2006) Prognostic Indicator Paper vs 2.25 www.goldstandardsframework.nhs.uk

Ellershaw, J.E & Wilkinson, S, (2003), Care of the Dying: a Pathway to Excellence, Oxford University Press Foote, C & Stanners, S, (2002), Integrating Care for Older People – New Care for Old – A Systems Approach, London, Jessica Kingsley

Khan, SA; Tarver, K; Fisher S; Butler C (2007), Inappropriate Amissions of Palliative Care Patients to Hospital: A Prospective Audit, London, Pilgrims Hospices

Harrison , S et al, (2008), Identifying Alternatives to Hospital for People at the End of Life, The Balance of Care Group / National Audit Office www.balanceofcare.co.uk

Pleschberger, S, (2007), Dignity and the Challenge of Dying in Nursing Homes:

The Residents' View http://ageing.oxfordjournals.org/content/36/2/197.short

Responsibility for delivery / implementation

HSC Trusts
Primary Care (including community pharmacy)
Voluntary palliative care providers
Private nursing homes

Quality Dimensions

Person Centred

- Earlier identification of palliative care needs and advance care planning will help improve quality of life and support a good death.

Effective

- Inappropriate admissions to hospital at the very end of life will be avoided.

Equitable

- People with non-cancer conditions will have access to care and services traditionally available mainly to those with cancer conditions only.

Performance Indicator:	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of the population that is enabled to die in their preferred place of care.	NISRA survey for baseline of the population's preference Registrar General and PAS information for actual place of death.	Baseline to be established Performance levels to be determined	March 2014
Percentage of population with an understanding of advance care planning.	NISRA survey for baseline levels.	Baseline to be established Performance levels to be determined	March 2014

APPENDICES
Appendix 1 – Section Leads

Section 6: Standards for Specific Conditions	**Section Lead(s)**
6.1 Chronic Obstructive Pulmonary Disease (COPD)	Dr Julian Leggett, NHSCT, Anne-Marie Marley, BHSCT
6.2 Oxygen Therapy in COPD	Deirdre Quinn, HSCB
6.3 Asthma in Adults	Prof. Liam Heaney, QUB / BHSCT
6.4 Asthma in Children and Young People	Dr Jenny Hughes, NHSCT
6.5 Community Acquired Pneumonia (CAP) in Adults	Dr Tim Warke, BHSCT & Dr Judith Ewing PHA
6.6 Community Acquired Pneumonia (CAP) in Children and Young People	Dr Gary Doherty, BHSCT
6.7 Obstructive Sleep Apnoea/Hypopnoea Syndrome in Adults	Dr Majella Tuohy, BHSCT
6.8 Obstructive Sleep Apnoea Syndrome in Children and Young People	Dr Dara O'Donaghue, BHSCT
6.9 Long Term Ventilation in Adults	Dr John McConville, SET
6.10 Long Term Ventilation in Children and Young People	Dr Gary Doherty, BHSCT
6.11 Cystic Fibrosis	Dr Jackie Rendall, BHSCT, Dr Alastair Reid, BHSCT
6.12 Bronchiectasis	Dr Gary Doherty, BHSCT / Jackie Rendall, BHSCT,
6.13 Interstitial Lung Disease (ILD)	Dr Eoin Murtagh, NHSCT
Section 7: Standards Relating to All Conditions	
7.1 Pulmonary Rehabilitation	Dr Brenda O'Neill, UU / Cathie McIlroy SHSCT
7.2 Transitional Care for Adolescents with Chronic Respiratory Disease	Dr Jenny Hughes, NHSCT / Prof. Mike Shields, BHSCT / Dr Alastair Reid, BHSCT & Dr Judith Ewing, PHA

7.3 Acute Oxygen Therapy	Anne-Marie Marley, BHSCT
7.4 Social and Emotional Support	Dr Jenny Gingles, PHA
7.5 Information	Dr Jenny Gingles, PHA
7.6 Training	Rose McHugh, PHA
7.7 Medicines Management	Deirdre Quinn, HSCB
Section 8: Standards for Supportive and Palliative Care	Dr Jenny Gingles, PHA

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An overarching project team was established, comprising of the following:

Dr Jenny Gingles – CHAIR (Public Health Consultant, PHA)	Rosa McCandless (Information services, HSCB)
Dr Brian Patterson, (Regional lead, ICPs)	Dr Richard Orr (Primary Care, HSCB)
Rose McHugh (Nursing, PHA)	Dr Terry Maguire (Chair, Belfast LCG)
Shane Breen (AHP consultant, PHA)	Gerry Bleakney (Health improvement, PHA)
Deirdre Quinn (Pharmaceutical services lead, HSCB)	Maeve Hully (Chief executive, PCC)
Dr Judith Ewing (Registrar, PHA)	Martin Quinn (Regional PPI lead, PHA)
Wendy Thornton (project manager, PHA)	Paul Cavanagh (Commissioning, HSCB)

Appendix 2 – Deaths by sex and cause, Northern Ireland 2001 to 2012

ICD 10 Code	Description	Sex	Number of Deaths by Cause											
			2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
J00-J99	**DISEASES OF THE RESPIRATORY SYSTEM**	M	891	806	928	893	866	884	921	944	901	856	850	977
		F	1,084	1,077	1,154	1,057	1,055	1,098	1,071	1,152	1,116	1,030	1,073	1,046
		All	**1,975**	**1, 883**	**2,082**	**1,950**	**1,921**	**1,982**	**1,992**	**2,096**	**2,017**	**1,886**	**1,923**	**2,023**
J09-J11	Influenza	M	0	0	1	1	0	0	0	0	7	4	11	1
		F	0	1	3	0	0	1	1	2	5	6	8	1
		All	**0**	**1**	**4**	**1**	**0**	**1**	**1**	**2**	**12**	**10**	**19**	**2**
J12-J18	Pneumonia	M	382	357	387	346	341	338	332	332	332	284	270	329
		F	646	594	638	563	554	557	527	568	488	453	467	477
		All	**1,028**	**951**	**1,025**	**909**	**895**	**895**	**859**	**900**	**820**	**737**	**737**	**806**
J40-J47	Chronic lower respiratory diseases	M	345	301	375	364	338	335	367	396	371	368	367	428
		F	291	306	336	317	313	336	326	364	415	369	407	377
		All	**636**	**607**	**711**	**681**	**651**	**671**	**693**	**760**	**786**	**737**	**774**	**805**

Source: NISRA - Registrar General Annual Report 2012

Appendix 3 – All Admissions and Hospital Bed Days by Primary Diagnosis, Northern Ireland 2012/3

Primary Diagnosis	ICD 10 CODE	Number of Admissions 2012/13	% of Total Respiratory Admissions	Number of Bed Days 2012/13	Percentage of Total Bed Days	Average length of stay (days)
Acute upper respiratory infections	J00-J06	5,161	15.2%	5,794	2.9%	1.1
Influenza and pneumonia	J09-J18	7,986	23.5%	76,810	38.0%	9.6
Other acute lower respiratory infections	J20-J22	6,925	20.4%	39,528	19.5%	5.7
Other diseases of upper respiratory tract	J30-J39	2,817	8.3%	3,873	1.9%	1.4
Bronchitis, Emphysema and other COPD	J40-J44	5,929	17.5%	37,196	18.4%	6.3
Bronchitis,Emphysema and other COPD as primary and first secondary diagnosis	*J40-J44*	*10,133*	*29.8%*	*69,099*	34.2%	*6.8*
Asthma	J45-J46	1,844	5.4%	5,213	2.6%	2.8
Bronchiectasis	J47	502	1.5%	3,868	1.9%	7.7
Lung diseases due to external agents	J60-J70	1,044	3.1%	13,988	6.9%	13.4
Other respiratory diseases principally affecting the interstitium	J80-J84	360	1.1%	3,266	1.6%	9.1
Suppurative and necrotic conditions of lower respiratory tract	J85-J86	71	0.2%	1,422	0.7%	20.0
Other diseases of pleura	J90-J94	806	2.4%	6,627	3.3%	8.2
Other diseases of the respiratory system	J95-J99	513	1.5%	4,626	2.3%	9.0
ALL RESPIRATORY*	**J00-J99**	**33,958**	**100.0%**	**202,211**	**100.0%**	**6.0**

*Excludes Bronchitis, Emphysema and other COPD as primary and first secondary diagnosis
Source: PASDSS/BOXi/Admissions and Discharges Universe (Run Date: 18/11/13)

Appendix 4 – Number of Admissions and Hospital Days for Asthma, COPD and Pneumonia – Northern Ireland 2008/9 – 2012/3

		2008/09	2009/10	2010/11	2011/12	2012/13
Asthma (J45 – J46)	Number of Admissions	1,945	1,842	1,713	1,619	1,844
	Hospital Days	6,154	5,629	4,909	4,676	5,213
COPD (J40-44)	Number of Admissions	5,257	4,583	5,034	4,979	5,929
	Hospital Days	43,489	35,000	35,250	33,272	37,196
Pneumonia (J13 – J18)	Number of Admissions	4,481	4,791	5,599	6,739	7,798
	Hospital Days	53,651	50,157	61,466	72,944	75,466

Source: PASDSS/BOXi/Admissions and Discharges Universe (Run Date: 18/11/13)

Glossary of terms

Acute	Of or relating to a disease or a condition with a rapid onset and a short, severe course
Adenotonsillar	Of or relating to the tonsils and adenoids
Allergic rhinitis	An inflammatory response in the nasal passages to an allergic stimulus
Alpha 1 Antitypsin	Deficiency of the protease inhibitor alpha-1 antitrypsin, leads primarily to degradation of elastin of the alveolar walls, as well as other structural proteins of a variety of tissues.
Alveoli	Tiny, thin-walled, capillary-rich sacs in the lungs where the exchange of oxygen and carbon dioxide takes place. Also called *air sac*
Alveolitis	Inflammation of alveoli
Anaphylaxis	Hypersensitivity induced by preliminary exposure to a substance and usually producing a contraction of smooth muscle and a dilation of blood vessels
Apnoea	An episode where normal breathing slows or stops completely.
ARTP	Association for Respiratory Technology and Physiology
Asbestosis	Fibrosis of the lung due to the inhalation of asbestos fibres
Atrophy	A wasting or decrease in size of a body organ, tissue, or part owing to disease, injury, or lack of use
Audit	Systematic review and evaluation of records and other data to determine the quality of the services or products provided in a given situation
Autosomal	A chromosome that is not a sex chromosome
BCG vaccination	Tuberculosis vaccine (Bacillus Calmette-Guerin)

Body Mass Index (BMI)	A measurement of the relative percentages of fat and muscle mass in the human body, in which mass in kilograms is divided by height in meters squared and the result used as an index of obesity
Bronchiectasis	A condition in which an area of the bronchial tubes is permanently and abnormally widened (dilated), with accompanying infection
Bronchoalveolar lavage	Irrigation or washing out of both the bronchia and alveoli of the lungs
Bronchodilators	A medication that acts to dilate (enlarge) the lumen of the airway to allow the unrestricted passage of air
Burkholderia cepacia	An important human pathogen which most often causes pneumonia in individuals (whose immune system is not fully functioning) ,who have underlying lung disease (such as cystic fibrosis or chronic granulatomous disease)
Cardiopulmonary	Pertaining to heart and lungs
Chronic	Lasting for a long period of time or marked by frequent recurrence
Chronic obstructive pulmonary disease (COPD)	A progressive disease process that most commonly results from smoking. Chronic obstructive pulmonary disease is characterised by difficulty breathing, and a chronic cough
Ciliary	A tiny hairlike projection on the surface of some cells and microscopic organisms
Clinical	Pertaining to or founded on actual observation and treatment of patients, as distinguished from theoretical or experimental
Cohort	A group of individuals sharing a common characteristic and observed over time in the group.
Commissioner	In the health service in Northern Ireland an individual or much more likely organisation which “purchases” services from local Health and Social Care Trusts in order to meet the health and social care needs of the population/area for which the commissioning body is responsible

Co-morbidity	Coexisting conditions or diseases with unrelated pathological or disease process
Contraindications	A factor that renders the administration of a drug or the carrying out of a medical procedure inadvisable.
Corticosteroids	Any of the steroid hormones produced by the adrenal cortex or their synthetic equivalents
Craniofacial	Of or involving both the cranium and the face
Craniopharyngioma	Craniopharyngioma is a cancer which arises in the pituitary gland, in tissue originally found in the embryo.
CPD	Continuing Professional Development
CRB-65 tool	This is a method of scoring severity of community acquired pneumonia in people aged more than 65, using scores relating to confusion, respiratory rate and blood pressure.
CREST	Clinical Resource Efficiency Support Team
Cystic Fibrosis	Cystic fibrosis (CF) is an inherited disease that affects the lungs, digestive system, sweat glands, and male fertility. Its name derives from the fibrous scar tissue that develops in the pancreas, one of the principal organs affected by the disease
Cytotoxic drugs	Drugs which act by killing or preventing the division of cells
DES	A Directly Enhanced Service is a specialised service provided by all GPs in N Ireland for Asthma and COPD.
Determinants	An influencing or determining element or factor
Duchenne Muscular Dystrophy (DMD)	A specific form of muscular dystrophy that is inherited as a sex-linked recessive trait and thus confined to young males and to females with Turner's syndrome
Dyskinesia	An impairment in the ability to control movements, characterized by spasmodic or repetitive motions or lack of coordination

Emphysema	A chronic lung disease characterised by progressive, irreversible expansion of the alveoli with eventual destruction of alveolar tissue, causing obstruction to airflow. People with emphysema often have laboured breathing, wheezing, chronic fatigue, and increased susceptibility to infection, and may require oxygen therapy. Long term smoking is a common cause of emphysema.
Empyema	The accumulation of pus in a cavity of the body, which when used in reference to respiratory disease, refers to thoracic empyema.
Endobronchial	Pertaining to or emanating from the lining of the bronchi.
Endotracheal	Within or passing through the windpipe
Equitable	Marked by or having equity; just and impartial
Exacerbation	An increase in the severity of a disease or in any of its signs or symptoms
Expert Patient Programme	A peer-led self care support programme for people living with any long term condition, their carer and families.
FEV1	Forced Expiratory Volume in 1 second (lung capacity test)
GINA Guidelines	Global Initiative for Asthma Guidelines
Glucocorticoid	Any of a group of anti-inflammatory steroid-like compounds, such as hydrocortisone, that are produced by the adrenal cortex, are involved in carbohydrate, protein, and fat metabolism, and are used as anti-inflammatory agents.
Granulatomous	Describes tumour-like mass or nodule of granulation (small, fleshy, beadlike protuberances) tissue
Green Book	Immunisations against infectious disease 2006 (Green Book) Joint Committee on Vaccination and Immunisation.
Hib	Haemophilus influenzae type b

High Resolution CT	High Resolution Computerised Tomography is a specialised radiological diagnostic test.
Holistic	Concerned with the whole person rather than analysis or separation of parts of the effects of a condition.
HSC Trusts	Health and Social Care Trusts
Hypercapnoea/Hypercapnia	A condition where there is too much carbon dioxide (CO_2) in the blood
Hypertrophy	A non-tumorous enlargement of an organ or a tissue as a result of an increase in the size rather than the number of constituent cells
Hypopnoea	Abnormally slow, shallow breathing
Hypoventilation	Abnormally slow and shallow respiration, resulting in an increased level of carbon dioxide in the blood
Hypoxaemia	Insufficient oxygenation of the blood
Hypoxia	Reduction of oxygen supply to tissue below physiological levels despite adequate perfusion of the tissue by blood
Idiopathic	Of or relating to a disease where there is no known cause
IgE mediated	IgE is the antibody that is involved in allergic reactions. A person who has an allergy produces too much IgE. This IgE may lead to the development of allergic symptoms. Hayfever is a well known example of this. IgE mediated means that the allergic reaction was set off by the production of too much IgE
Immunodeficiency	An innate, acquired, or induced inability to develop a normal immune response
Immunosuppressed	Suppression of the immune response, as by drugs or radiation, in order to prevent the rejection of grafts or transplants or to control autoimmune diseases.
Incidence	Extent or frequency of occurrence
Inflammatory Bowel Disease	A general term that encompasses several disease processes, most commonly, ulcerative colitis and Crohn’s disease

Intermediate care	A level of medical care in a hospital that is intermediate between intensive and basic care
Interstitium	Small interval, space, or gap in a tissue or structure.
Intra-oral devices	Gumshield-like devices (mandibular repositioning devices) which attempt to keep the airway clear by moving the jaw forward.
IRT test	Immunoreactive trypsin (IRT) is used to selectively screen for cystic fibrosis (CF) in new-born infants.
Kyphoscoliosis	Upward (kyphosis) and lateral (scoliosis) curvature of the spine.
Longitudinal	Concerned with the development of persons or groups over time
Mono-specific	Having an effect only on a particular kind of cell or tissue or reacting with a single antigen
Mortality rate	The death rate; the ratio of the total number of deaths to the total number of the population during a specified time period.
M.TB	Mycobacterium tuberculosis – The Gram-positive bacterium that causes tuberculosis
Musculoskeletal	Relating to or involving the muscles and the skeleton
Nasal polyps	Usually non malignant growth of tissue protruding from the mucous lining of the nose
Nebuliser	A device used to reduce liquid medication to extremely fine cloudlike particles; useful in delivering medication to deeper parts of the respiratory tract.
Neuromuscular	Pertaining to muscles and nerves
NICE	National Institute for Health and Clinical Excellence
NICaN	Northern Ireland Cancer Network

Non-caseating granulomas	Granulomas are small nodules seen in a variety of diseases. An important feature is whether they are caseating or not. Caseation is necrosis at the centre of the granuloma
Obstructive Sleep Apnoea Syndrome	A form of sleep apnoea which occurs as the result of a physical occlusion of the oropharyngeal airway during sleep
Omalizumab	A monoclonal antibody used as a parenteral drug to treat severe asthma
Oximetry	Measurement of the oxygen content of arterial blood.
Palliative care	Care that relieves or soothes the symptoms of a disease or disorder without effecting a cure
Parenchymal lung disease	Disease which impacts on the lungs' essential function
Pathological	Relating to or caused by disease
Peak flow measurement	Measurement of maximum breathing capacity of an individual
PEFR	Peak Expiratory Flow Rate
Pertussis	Whooping cough
PICU	Paediatric Intensive Care Unit
Pleural	Refers to the pleura or membrane that enfolds the lung
Pneumococcal vaccine	This is a vaccination which protects against diseases caused by a bacterium called Streptococcus Pneumoniae, including pneumonia.
Polysomnography (PSG)	Simultaneous and continuous monitoring of normal and abnormal physiological activity during sleep
Prader Willi Syndrome	A congenital syndrome of unknown cause characterized by short stature, mental retardation, excessive eating and obesity, and sexual immaturity
Prevalence	The total number of cases of a disease in a given population at a specific time
Primary care	The initial medical care given by a health care provider to a person outside hospital, usually a GP

Pseudomonas aeruginosa	A bacterium which is a common isolate from wounds, burns and urinary tract infections and from many other accumulations of pus in all species
Pulmonary	Of, relating to, or affecting the lungs
Pulmonary fibrosis	Scarring in the lungs
Radiological	Pertaining to the branch of the health sciences which deals with radioactive substances and radiant energy and with the diagnosis and treatment of disease by means of both ionizing (e.g. x-rays) and non ionizing (e.g., ultrasound) radiation
Respiratory acidosis	Acidosis is an abnormal increase in the acidity of the body's fluids, caused either by accumulation of acids or by depletion of bicarbonates. In respiratory acidosis it is caused by retention of carbon dioxide, due to inadequate pulmonary ventilation or hypoventilation
Rheumatoid arthritis	Chronic inflammatory disease in which there is destruction of joints
Sarcoidosis	Disease of unknown origin marked by formation of granulomatous (small nodules of inflammatory tissue) lesions that appear especially in the liver, lungs, skin, and lymph nodes
Scoliosis	A congenital lateral curvature of the spine
Secondary care	Treatment by specialists to whom a person has been referred by primary care providers usually in a hospital setting
Sinusitis	Inflammation of the mucous membrane of a sinus
Short-acting broncho-dilators (SABAs)	Bronchodilators are drugs which dilate bronchi and bronchioles. Bronchodilators are either short-acting or long-acting. Short-acting medications provide quick or "rescue" relief from acute bronchoconstriction. Long-acting bronchodilators help to control and prevent symptoms

Spinal Muscular Atrophy (SMA)	Progressive degeneration of the motor cells of the spinal cord, beginning usually in the small muscles of the hands, but in some cases (scapulohumeral type) in the upper arm and shoulder muscles, and progressing slowly to the leg muscles.
Spirometry	Test using an instrument (a spirometer) for measuring the volume of air entering and leaving the lungs
Sputum	Matter coughed up and usually expelled from the mouth, especially mucus or mucopurulent matter expectorated in diseases of the air passages
Symptomatic	Characteristic or indicative of a disease
Tertiary care	Treatment given in a health care centre that includes highly trained specialists and often advanced technology
Thoracic	Of or pertaining to the chest
Thoracoabdominal	Relating to the thorax and the abdomen
Tuberculosis	A disease caused by an infection with the bacteria Mycobacterium tuberculosis
Venturi mask	A type of disposable mask used to deliver a controlled oxygen concentration to a person
Video-assisted thoracoscopy	Endoscopic (use of an illuminated, flexible optical tube) examination of the chest cavity
Workers’ pnuemoconiosis	Deposition of large amounts of dust or other particulate matter in the lungs, causing a tissue reaction, usually in workers in certain occupations and in residents of areas with excessive particulates in the air

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