The Regulation and Quality Improvement Authority

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Independent Review of the Implementation of the Respiratory Service Framework

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Assurance, Challenge and Improvement in Health and Social Care

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The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland.

RQIA's reviews are designed to identify best practice, to highlight gaps or shortfalls in services requiring improvement, and to protect the public interest.

Our reports are submitted to the Minister for Health, Social Services and Public Safety and are available on the RQIA website at www.rqia.org.uk.

Executive Summary

The Service Framework for Respiratory Health and Wellbeing is the second of a programme of service frameworks to be launched in Northern Ireland. The framework set out 55 standards for the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities at greater risk of developing respiratory disease.

The framework was launched at a time when the organisational and financial context in Northern Ireland was changing significantly. In 2009, a new HSC organisational structure was established with the formation of the Health and Social Care Board (HSCB) and the Public Health Agency (PHA). The wider context continues to evolve and the framework is now being reviewed to ensure continuing improvement in respiratory services.

RQIA found widespread support among stakeholders for the service framework approach. There was a clear consensus that the framework had established a vehicle to realise the goals and objectives of the Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006)[1]. The partnership approach adopted during development of the framework had created a positive platform, from which to launch the implementation process.

The review team found that collaboration with service users, stakeholders and the public was well planned, and to the forefront of both the development and the implementation of the Respiratory Service Framework. Voluntary agencies reinforced the benefits of joint working between voluntary and statutory services. They considered the implementation process to have been a success that shaped the way services are being taken forward, and the framework contributed significantly to improvements in respiratory services.

From the learning from this review, RQIA makes six recommendations for the implementation arrangements for future service frameworks. The identified regional lead for implementation should be provided with appropriate support. For each framework a regional network should support the implementation process. A standard approach, with a small number of high level indicators to monitor progress should be agreed. This approach should include an agreed formal change management process. Consideration should be given to the development of a set of service specifications to facilitate commissioning arrangements for the standards within the framework

Finally RQIA would also recommend that arrangements for disseminating information about the range of both voluntary and statutory services are reviewed. This will ensure that referring practitioners have a clear understanding about the services available in their area.

[1] Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006)http://www.dhsspsni.gov.uk/pcd_-_respiratory_framework.pdf

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1. Introduction and Background to the Review

1.1 Service Frameworks in Northern Ireland

In a letter dated 1 March 2007, the Chief Medical Officer (CMO) and the Deputy Secretary, Department of Health, Social Services and Public Safety (DHSSPS) announced that DHSSPS had commenced the development of a programme of service frameworks. These service frameworks would set out standards for health and social care. Patients, clients, carers and their wider families should be able to use the frameworks to understand the standard of care that they could expect to receive. Health and social care (HSC) organisations would use them when planning and delivering services.

A service framework is a document which contains explicit standards, underpinned by evidence and legislative requirements. Service frameworks set targets, timeframes and expected outcomes for specific services, and are designed to:

- improve the health and social wellbeing of the population of Northern Ireland,
- reduce inequalities and promote social inclusion,
- improve the quality and safety of care,
- safeguard vulnerable individuals and groups,
- improve partnership working with other agencies and sectors.

Service frameworks link to key policies and strategies already developed, and draw on evidence from established sources, including the National Institute for Health and Care Excellence (NICE) and the Social Care Institute for Excellence (SCIE).

Service frameworks are a major element of the service reform programme for health and social care in Northern Ireland. They are designed to be used by the public, commissioners and providers of services, and those organisations that report on the performance and quality of services.

The development of service frameworks is being led by DHSSPS and is undertaken in partnership with organisations from statutory, voluntary and community sectors, as well as service users and carers. Where appropriate, they are developed in collaboration with established networks and groups.

Each service framework includes a multidisciplinary approach, recognising that the majority of care is delivered in primary and community care, with active participation of individuals and carers. In addition, service frameworks recognise that the provision of care can go beyond traditional HSC boundaries.

Each service framework is subject to formal consultation. The results are analysed and a final framework is produced, together with an easy access version. Further information and detail on the standards, rationale, criteria, performance indicators and audit criteria is publicly available on the DHSSPS website.[2]

[2] http://www.dhsspsni.gov.uk/rsf_-_full_document.pdf

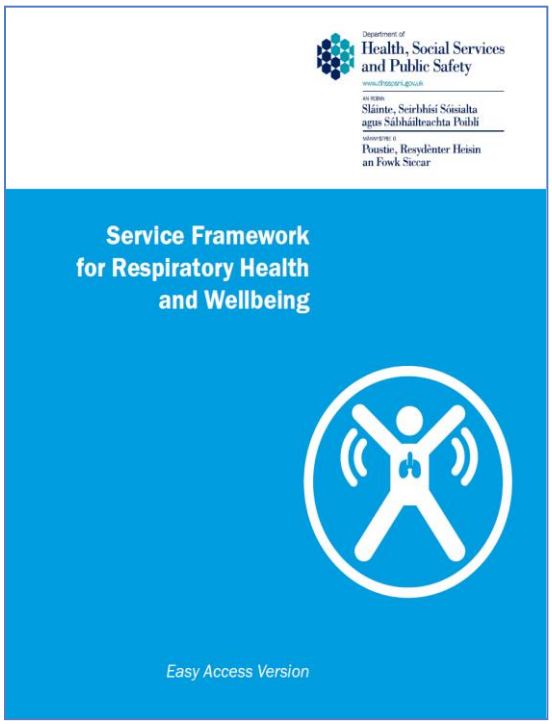
The first group of frameworks focused on the most significant causes of ill health and disability in Northern Ireland. The service framework for Respiratory Disease was the second to be completed, in November 2009.

In a letter from the Chief Medical Officer, dated 22 December 2011, accountability for the implementation of all service frameworks was strengthened. DHSSPS now seeks assurance about outcomes at twice yearly accountability meetings with the HSC Board (HSCB) and the Public Health Agency (PHA). In his letter the CMO stated 'It will be for the HSC Board/PHA to secure assurance on progress made against standards and indicators from individual trusts and other service providers, where relevant.' RQIA has been commissioned to carry out a review of the implementation process for each framework three years after it is launched.

The Respiratory Service Framework is the second to be the subject of an implementation review by RQIA. A review of the implementation of the Cardiovascular Service Framework was published in November 2012.

1.2 The Respiratory Service Framework

The Service Framework for Respiratory Health and Wellbeing (the Respiratory Framework) was formally launched by the Minister for Health Social Services and Public Safety in November 2009.



The framework sets out 55 standards for the prevention, diagnosis, treatment, care, rehabilitation and palliative care of individuals and communities at a greater risk of developing respiratory disease. Each standard was supported by key performance indicators, which set levels of performance to be achieved over the three-year period 2009-12.

Recognising that several diseases can co-exist, share common risk factors and can adversely impact on prognosis, the service framework included both standards for specific respiratory conditions and generic standards relating to a range of conditions.

Standards for specific respiratory conditions

- Chronic Obstructive Pulmonary Disease (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 in Adults
- Obstructive Sleep Apnoea Syndrome in Children and Young People
- Long Term Ventilation in Children and Young People
- Cystic Fibrosis
- Bronchiectasis
- Tuberculosis
- Interstitial Lung Disease (ILD)

Standards relating to all respiratory conditions

- Nebuliser Treatment
- Pulmonary Rehabilitation
- Transitional Care for Adolescents with Chronic Respiratory Disease
- Lung Transplantation
- Acute Oxygen Therapy
- Social and Emotional Support
- Information

The Respiratory Service Framework also has standards on communication, participation, health promotion and palliative care.

The standards in the Service Framework for Respiratory Health and Wellbeing are set out in Appendix A.

A full copy of the service framework can be found on the DHSSPS website http://www.dhsspsni.gov.uk/sqsd-service_frameworks_respiratory.

1.3 The impact of Respiratory Disease in Northern Ireland

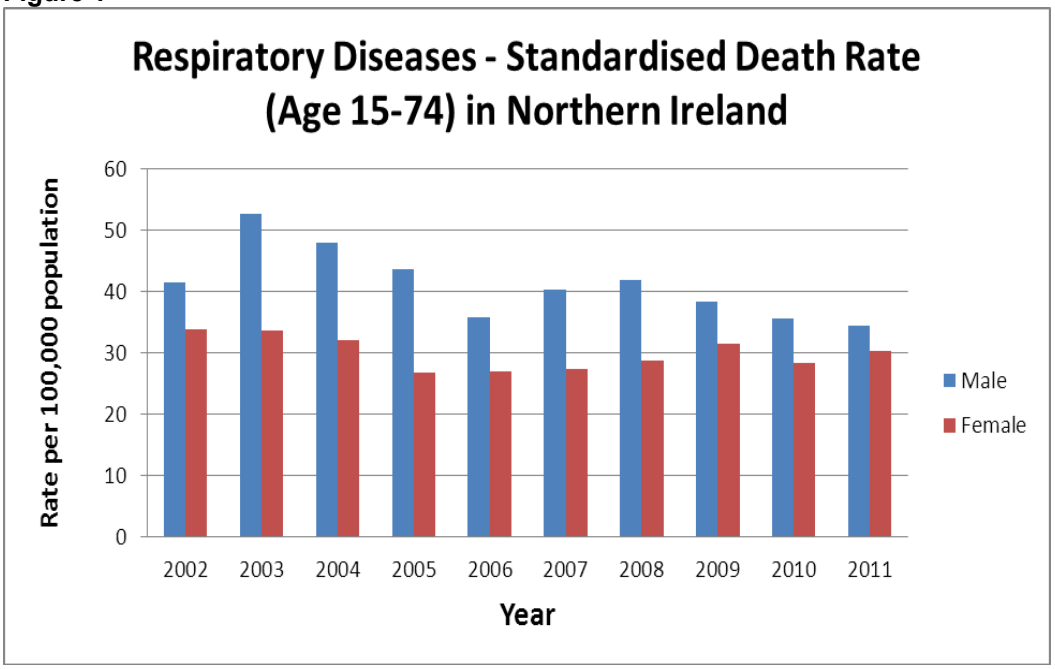
The term respiratory disease encompasses a wide range of illnesses affecting both the upper and lower respiratory tracts. Patients with respiratory disease often require the expertise of a range of health and social care professionals who have specialised skills in the field of respiratory care. Some conditions affecting the respiratory tract require the care of professionals in other disciplines such as cardiovascular medicine, ear, nose and throat surgery, immunology or oncology.

Respiratory diseases are extremely common in Northern Ireland. In 2012, a total of 2023 deaths were attributed to respiratory disease; 977 male deaths and 1046 female deaths[3].

[3] Source: NISRA: Registrar General Annual Report, 2012

Figure 1 illustrates the trends in respiratory disease mortality rates for men and women aged 15 to 74 from 2002 to 2011. Death rates vary between years. Death rates over this period have fallen to some extent for men, but this is not clearly seen for women. The standardised death rates represented in the graph are calculated to compare trends, having taken account of changes in the age of the population.

Figure 1



Source: Core Tables 2011: Director of Public Health Annual Report (2012)

Respiratory diseases are also the cause of significant disability in our communities, particularly amongst children and the elderly. From GP registers it is estimated that 2% of the population have chronic obstructive pulmonary disease, and a further 6% have asthma.[4]

Hospital admission rates for respiratory diseases in Northern Ireland (all ages) increased between 2000-02 and 2008-10, from 1524 to 1633 admissions per 100,000 population[5].

While respiratory diseases affect all sections of the population, they disproportionately affect those who are most disadvantaged in our society.

In 2006-10 the death rate from respiratory diseases in the most deprived areas was almost three times higher than in the least deprived areas. Hospital admission rates for the most deprived areas were four-fifths higher than the least deprived areas in 2008-10[6].

[4] DHSSPS; NI Health and Social Care Inequalities Monitoring System Fourth Update Bulletin, June 2012
[5] As 2 above
[6] As 2 above

1.4 Key findings from the RQIA Review of the implementation of the Cardiovascular Service Framework

In 2012, RQIA undertook an independent review of the implementation of the Service Framework for Cardiovascular Health and Wellbeing. The report, published in November 2012, made ten recommendations for improvement.

RQIA found widespread support among stakeholders for the service framework approach. The Cardiovascular Service Framework was considered to have facilitated service improvement and development. Examples of specific developments which had taken place since the framework was launched included the establishment of a consultant post for adults with congenital heart disease, a screening programme for abdominal aortic aneurysm, and fast tracking of thrombolysis for stroke patients.

In 2009, at the time of launch of the framework, there was no agreed implementation plan for the service framework, this was subsequently developed. Accountability arrangements for service framework implementation and monitoring were clarified and strengthened in 2011 through the issue of a letter from the Chief Medical Officer.

Significant challenges emerged during the three-year period of implementation, which included:

- lack of available information to allow monitoring of progress against the standards in the framework
- changes in organisational structures
- financial pressures restricting available resources for implementation

RQIA concluded that, from the evidence collected in that review, key lessons for the implementation of future service frameworks included:

- the development of a service framework provides the opportunity to create a common vision for service development between commissioners, providers, patients and staff,
- there is a need to plan mechanisms to ensure that an effective engagement process is maintained after a framework is launched, to avoid loss of momentum,
- implementation of a service framework requires clear organisational accountability and is facilitated by having a designated regional lead,
- clinical networks with strong patient and service user engagement can play a key role in the implementation process,
- a small number of high level indicators should be agreed to monitor progress on the framework.

2. Terms of Reference

The terms of reference for this review were to:

1. Appraise the implementation process for the Respiratory Service Framework within HSC organisations.
2. Consider the effectiveness and impact of the Respiratory Service Framework process, on the delivery and development of services, in the 3 years since its launch.
3. Obtain the views of staff, voluntary agencies and service users involved in the implementation process of the Respiratory Service Framework.
4. Identify any lessons learned from the implementation of the Respiratory Service Framework which are relevant to the implementation of future and existing frameworks within the HSC.
5. Report on the findings and make recommendations for improvement which will inform the planned substantive end of life cycle review of the Respiratory Service Framework.

3. Methodology

The methodology adopted for this review was designed to gather the views of a wide range of people who were involved in the implementation of the Respiratory Service Framework.

In order to ensure engagement across the different areas covered by the framework RQIA spoke to people with interests in a number of specific conditions including COPD, Asthma, Obstructive Sleep Apnoea and Cystic Fibrosis.

Perspectives were sought regarding the implementation process from voluntary agencies, patient representative groups and others with a specific interest in the Respiratory Service Framework. The methods used included:

1. Desktop research was undertaken to examine the context in which the Respiratory Service Framework was established and developed. Lines of enquiry were developed to explore the implementation process and the impact this has had within health and social care.

2. Information gathering interviews were held with key staff involved in the implementation process, to explore their experiences and perspectives regarding the effectiveness of the process.

3. A semi structured questionnaire was developed, using the five key principles set out in Wilcox: The Guide to Effective Participation [7]:

[7] Wilcox: The guide to effective participation was published in 1994 and was supported by the Joseph Rowntree Foundation as part of its programme of research and innovative development projects. Designed to be of value to policy makers and practitioners, it provides both a theoretical framework for common understanding and a dictionary to facilitate the dialogue that can lead to successful participation. http://www.partnerships.org.uk/guide/

- information giving
- consultation
- deciding together
- acting together
- supporting

3. Interviews were held with service users, voluntary bodies and patient representatives. Each of these interviews used a semi-structured interview approach with specific questions designed by the RQIA review team.

4. The initial findings from the interviews were collated. The emerging findings were presented and discussed at a summit event, involving service user representatives, voluntary organisations and HSC organisations. This allowed for the information previously collected to be consolidated and for participants to suggest ideas to improve the implementation process for service frameworks in the future.

RQIA wishes to thank all those people, including service users, voluntary agencies and HSC staff, who facilitated this review through participating in interviews, attending the summit event or providing relevant information.

4. Findings

4.1 Introduction

The process for development of service frameworks in Northern Ireland is specifically designed to ensure involvement of patients, service users and clinicians. There was extensive partnership working across the HSC and voluntary agencies during the development of the respiratory service framework.

The development of the framework drew significantly on previous work to prepare a Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006).

RQIA found that there was a clear consensus that the framework had established a vehicle to realise the goals and objectives of the strategy. Individuals advised RQIA that the launch of framework had provided direction and legitimacy to the work they had previously undertaken.

Individuals emphasised that the partnership approach during development had created a positive platform from which to launch the implementation process. The widespread engagement had created an established network of contacts, good working relationships, and enthusiasm among staff. This ensured buy-in and support for the implementation of the framework when it was launched.

RQIA was provided with documentation relating to the period from the development of the service framework and during the implementation process, for the period 2009 to 2012. Using the information provided, a timeline of key events was prepared to help understand the process of development and the implementation of the framework. This is set out at Appendix B.

To inform the review, interviews were held with a cross-section of individuals who had been involved throughout the implementation process. This aim of this report is to capture their experiences and perspectives on the effectiveness of the implementation process, the successes achieved and the challenges which emerged.

As part of the review methodology, RQIA hosted a stakeholder summit event in August 2013. This event provided an opportunity for a range of key staff from across Health and Social Care to discuss the initial findings of the review and to evaluate the progress made on the implementation of the Respiratory Framework.

At the summit the initial findings of the review were presented and it was agreed that the issues identified represented a fair reflection of the work undertaken in progressing the framework. There was a general consensus that the framework had facilitated service improvement and development during the implementation period. However there was a strongly held view that momentum needed to be maintained for this and future frameworks.

Participants used this opportunity to discuss the findings and propose suggestions to improve or enhance the implementation of future service frameworks. Their views are reflected in this report.

4.2 Implementation requirements

In March 2009, the regional document, Priorities for Action[8], set out the requirements placed on HSC organisations for the initial phase of implementation of the Respiratory Service Framework by March 2010. In a letter, dated 25 November 2009, DHSSPS asked HSCB and PHA to adopt a phased approach to implementation as outlined below:

1. All standards for which there was already a data source in place were to be fully implemented by March 2010.

2. By March 2010, for the remaining standards, appropriate steps were to be taken to establish data sources and baselines. Performance levels for these standards were to be determined once baselines had been established.

When the Respiratory Service Framework was launched in November 2009, there was no specific regional blueprint for the implementation process. However, in a letter dated 25 November 2009, DHSSPS asked HSCB and PHA to:

- develop a plan for the phased implementation of the Respiratory Service Framework,
- identify a senior professional to lead the implementation process,
- submit a jointly agreed plan by 31January 2010 for the phased implementation of the framework by March 2012,
- provide assurance to the DHSSPS in relation to the achievement of the framework standards on a six monthly basis.

4.3 Implementation Structures

RQIA was advised that the implementation structures to take forward the Respiratory Service Framework have evolved throughout the period of implementation, to reflect emerging issues and requirements.

Initial arrangements

In 2009 following the launch of the framework, HSCB and PHA identified a public health consultant as the lead for both organisations in taking the framework implementation forward.

A plan was developed for the phased implementation of the framework. It was agreed that implementation would be overseen by a Respiratory Health and Wellbeing Implementation Group. This group would work jointly with HSCB and PHA, in relation to the development of strategies and plans to improve the respiratory health of the population. The remit of the group was to:

- Champion the Respiratory Service Framework.

[8] Priorities for Action 2009-10 DHSSPS, March 2009

- Consider all aspects of respiratory health and wellbeing: ranging from primary prevention, through primary, secondary, and tertiary care, to rehabilitation and end of life care.
- Identify commissioning priorities and develop plans in relation to respiratory health improvement for HSCB, PHA and other stakeholders such as primary care (including community pharmacy).
- Maintain close links and partnership working with local commissioning groups[9] (LCGs), primary care, the respiratory forum and local respiratory groups.
- Link into the HSCB/ PHA performance arrangements in relation to monitoring, and reporting on, progress towards ministerial and other targets; including implementation of the Respiratory Health and Wellbeing Service Framework.
- Continually review and monitor Respiratory Service Framework quality indicators to ensure compliance with emerging evidence based best practice.
- Benchmark the on-going delivery of respiratory services and work to deliver service improvements.
- Report progress to senior management teams at HSCB and PHA and to the DHSSPS as required.

Following discussions with group members, voluntary agencies and the Patient and Client Council, it was decided to establish an on-going and comprehensive patient/client participation system. The aim was to ensure feedback was obtained from the wide range of services and geographical areas; and allow a large number of patient and carers to be represented and supported.

The work of the Respiratory Health and Wellbeing Implementation Group was supported by a group which already existed, with representation from statutory and voluntary providers called the Regional Respiratory Forum.

The Respiratory Health and Wellbeing Implementation Group met regularly at the start of the implementation process. It was chaired by the implementation lead and included representation from organisations accountable for the commissioning and delivery of respiratory services. It brought a focus to the implementation process at this initial period.

Development of revised structures

As implementation progressed it was found that the Respiratory Health and Wellbeing Implementation Group was not required to meet regularly. Primary responsibility for the implementation process was then transferred to the Regional Respiratory Forum.

[9] Local Commissioning Groups (LCGs) are responsible for the commissioning of health and social care by addressing the care needs of their local population. They also have responsibility for assessing health and social care needs; planning health and social care to meet current and emerging needs; and securing the delivery of health and social care to meet assessed needs.

RQIA was advised as to how the arrangements had evolved to meet challenges and to take forward specific initiatives. At the centre of the arrangements, the Regional Respiratory Forum was widely considered to have a critical role in coordinating the implementation of the framework.

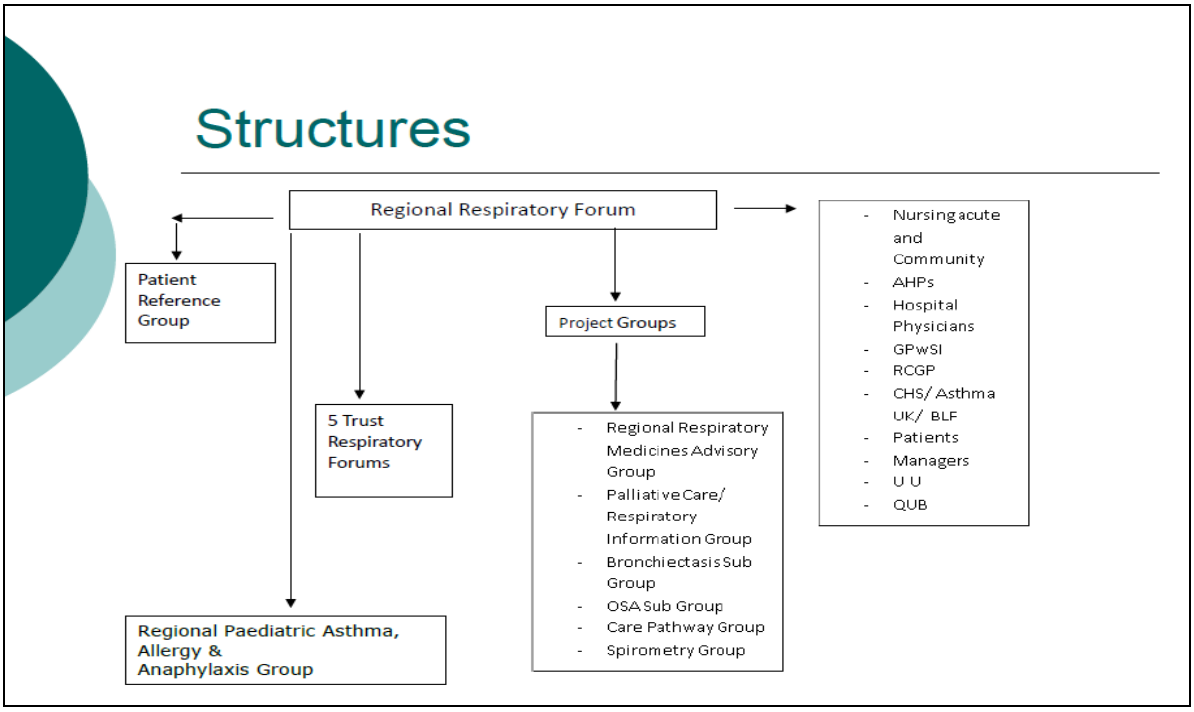
To support the work of the Regional Respiratory Forum, a number of subgroups were set up. Each subgroup is represented on the Regional Respiratory Forum, which also has representation from Local Commissioning Groups (LCGs) and from voluntary sector organisations. The subgroups have a number of functions including:

- providing an advisory role in relation their specific area of interest
- highlighting areas of need for service development
- monitoring initiatives
- promoting best practice
- training and education

During development of the standards there were a number of workshops involving the public. It had been hoped to maintain this engagement throughout the implementation of the framework through the development of a patient reference group, however such a group was never established.

Despite this, when the framework was launched, the issues identified from previous patient engagement were recognised. Patient engagement has continued via the involvement of voluntary agencies in the implementation process.

The diagram below illustrates the structures which were in place by 2013 to take forward the implementation of the framework. These had evolved significantly since the original design in 2010.



The roles of groups within the implementation structure are described below

Trust Respiratory Forums

Each trust has a local respiratory forum, which has a key role at trust level to ensure that plans are made to meet standards and performance indicators. These groups have multidisciplinary input and include representation from general practitioners, with managerial and clinical input.

The local respiratory forums were set up to implement the framework and they report upwards via the Regional Respiratory Forum to the HSC Board. These forums have the local knowledge to assess the current situation and progress on implementation. This in turn allows for effective planning for future service developments.

Regional Respiratory Nurses Forum

The Regional Respiratory Nurses Forum was in place before the framework launch, however membership has increased since the launch of the framework. The forum was originally established by a dedicated group of staff who discussed the requirements of the document and how these could be delivered. Essentially this brought together people from a number of multidisciplinary backgrounds to share best practice and to progress the framework together.

A similar group for physiotherapists has been established following the launch of the framework. It is hoped that in the future these two groups will meet to share their experiences and learning and to take forward best practice in respiratory services.

Regional Paediatric Respiratory, Allergy and Anaphylaxis Group

A Regional Paediatric Respiratory, Allergy And Anaphylaxis Group was established prior to the launch of the Respiratory Services Framework. This network developed in order to improve services. However, it has since evolved and was used as the basis for implementation of paediatric standards. The group is multidisciplinary and includes service user representation.

The Regional Paediatric Respiratory, Allergy And Anaphylaxis Group provides an arena through which initiatives being undertaken in individual trusts can be shared, thus ensuring there is learning through sharing of best practice across organisations. Representatives from the network also sit on the Regional Respiratory Forum and this ensures appropriate information sharing between groups and across the wider network of subgroups.

Regional Respiratory Medicines Advisory Group

The Regional Respiratory Medicines Advisory Group was set up to provide expert advice on the use of medicines and appliances for the treatment and prevention of respiratory diseases in adults and children. The group membership has been based on individual’s expertise in respiratory medicine.

The group exists to:

- make recommendations for policy and strategy development and provide direction to the therapeutic management of respiratory diseases across the HSC,
- inform the constitution of any working groups identified by the group,
- provide professional expertise to inform the specification for the oxygen tender process,
- provide professional expertise to the development of prescribing guidelines and formulary development for respiratory diseases,
- provide professional input into the evaluation of respiratory medicines and products to be included in the primary/secondary care contract utilising steps select methodology (clinical evaluation, safety and risk evaluation and budgetary impact assessment),
- provide professional advice and support to commissioners and the regional respiratory forum, on the implementation of those aspects of the respiratory services framework which have medicines related recommendations.

Other Project Groups

Under the Regional Respiratory Forum a number of smaller subgroups were established tasked with taking specific pieces of work forward. These include:

- palliative care/respiratory information sub group
- bronchiectasis sub group
- obstructive sleep apnoea sub group
- care pathway group
- spirometry group

Some of these groups were time limited and then stood down; others have evolved and changed direction in tandem with the progress made. There was overlap between these groups which often had shared membership and there was regular reporting to the forum.

Each of these groups has multidisciplinary membership from across all trusts. They feedback ultimately to the implementation lead who then reports to the HSCB/PHA and the DHSSPS.

4.4 Implementation processes

Taking forward the Respiratory Service Framework has involved a number of important implementation processes. RQIA has been advised that alongside the changes in structures, implementation processes also evolved during this period.

Development of Service Specifications

During the development of the framework there was extensive consultation before publication. The framework was also subject to a costing exercise. At this stage all measurement issues and solutions were considered. Service specifications were chosen as one way to inform commissioners and measure performance indicators. A project management post was funded by the DHSSPS to support this process.

Service specifications were designed for all services, primary, community and hospital; as well as health promotion and palliative care. They included the chronic disease management model, integrating self-management, disease pathways, training competencies and monitoring processes.

HSC Trusts were subsequently asked to complete self-assessment proformas which were used in conjunction with bench marking information on service provision, standardised usage data and audit to ensure that standards were being met.

RQIA found that the development of service specifications was considered to have greatly facilitated the implementation process. They did assist in enabling monitoring of the framework. However, concern was expressed that the process could not be maintained using the existing manual process and there was a need to establish an improved system of collecting information in relation to performance against the standards.

Information to support the implementation of the framework

The implementation lead and other interviewees advised RQIA that there had been significant difficulties in gathering information to assess progress against the standards in the framework. For example, issues had included the lack of standardisation of information and systems across Northern Ireland. Diagnostic information was also not coded at outpatients.

To overcome these challenges, the implementation lead sought information from a wide range of sources, such as Quality and Outcomes Framework data from primary care, voluntary agency surveys and other health surveillance data held at regional or trust level.

Plans were made to implement a number of database developments and funding and support was obtained from the Performance Management and Service Improvement Directorate (PMSID) to:

- develop a number of regional paediatric databases;
- develop the community information system for palliative care;
- secure agreement that outpatient coding from the Patient Administration System could be used for respiratory conditions;
- pilot an outpatient database for Interstitial Lung Disease **(**ILD)/Bronchiectasis.

A member of PHA staff from Health Informatics was involved during the initial period who provided consistent support during the first and second year of data collection. However in year 3 this support was no longer available.

RQIA found that, while there were challenges, it had been possible to develop monitoring arrangements for many of the standards.

Monitoring arrangements

To facilitate monitoring of progress of implementation of the framework, a red/amber/green (RAG)[10] template was developed. This is completed at least annually and is supported by a service specification breakdown.

RQIA was informed that the RAG update was a useful operational tool. Staff described how they are able to use the Key Performance Indicators, associated with the standards within the framework, as drivers to move implementation forward and to improve services. The RAG update provides a clear position statement which can be used to demonstrate progress and identify areas which require on-going action.

RQIA was advised that the PHA and the HSCB has been working jointly to simplify and standardise the monitoring processes for service frameworks.

It is recognised that measuring health outcomes directly related to the service framework is difficult in chronic respiratory diseases. These can relate to a wide range of interconnected processes, assessments and treatments.

Clinical audits

RQIA was advised that clinical audit has been used to assist in taking forward the framework, and assessing progress against standards.

The implementation lead successfully applied for funding from the Guidelines and Audit Implementation Network (GAIN) to help establish the baseline from which measurement of service framework standards can be recorded. GAIN supplied funding support to Trusts to enable them to carry out data input for these audits. Throughout the three year implementation period a number of audits were carried out with the support of GAIN funding, including Long Term Oxygen Therapy (LTOT) and Asthma audits. The review team were advised that GAIN support was vital for progressing regional and local audits. Without it, there would have been marked difficulties in implementation.

The Regional Paediatric Respiratory, Allergy and Anaphylaxis group coordinates British Thoracic Society (BTS) audits which take place annually across the UK. The BTS has provided an easy to use interface whereby information is uploaded, analysed and then used to provide benchmarking information across other trusts and throughout the UK.

BTS audits were also used widely across adult service including **c**ommunity acquired pneumonia (CAP), the European COPD audit and Bronchiectasis audit. BTS audits data collated across Northern Ireland for bench marking. Audits have also been undertaken in a number of other areas including pneumonia, asthma and anaphylaxis self-management plans.

These audits provide opportunities to compare practice and promote reflective practice among clinicians. RQIA was advised that there has been good

[10] The current RAG coding system uses a 4 colour system to monitor and record standards as achieved, substantially achieved, partially achieved and not achieved.

engagement with clinicians and there is a desire to strive for improved outcomes for the patient. While audit can be labour intensive it does help to ensure a strong focus on quality of services for patients.

Accountability Arrangements

In December 2011 accountability for the implementation of all service frameworks was strengthened. DHSSPS now seeks assurance on progress at twice yearly accountability meetings with the HSCB and PHA.

The HSCB and PHA are required to secure assurance on progress made against standards within the framework from individual trusts and other service providers. In response to this PHA and HSCB have been working jointly to simplify and standardise the monitoring and accountability processes for service frameworks.

Since October 2012, an update on progress is prepared by the PHA on a six monthly basis and a standardised progress report is compiled to coincide with the accountability meetings with the DHSSPS.

The progress report provides a brief qualitative update on the progress made in the implementation of the framework, including the key achievements since the last report, and the priorities for the next 6 month period. It describes any risks, constraints and key challenges, and provides a specific update on any key performance indicators (KPI) which have not progressed as expected. This report is supported by a quantitative RAG report which outlines the progress made against each of the 55 standards within the framework.

Before the accountability review this report is shared with the senior management teams from each organisation and with the governance team in the HSC Board, so that any emerging risks can be identified.

Resources for the implementation of the framework

In 2009 at the launch of the Respiratory Service Framework the DHSSPS indicated that the framework would be underpinned by a significant investment of £6.5 million and an additional £3.2 million investment in general medical services for the treatment of COPD and asthma.

The resource environment changed significantly during the period of the framework implementation and the planned investment was not fully allocated. Service developments had to compete alongside other competing commissioning priorities at commissioner level, and with individual financial pressures within trusts.

At commissioner level, several detailed costing exercises were carried out to determine the financial implications of implementing the Respiratory Service Framework. A chronic disease management model approach was used for determining needs. Basic service templates were developed and a needs assessment exercise carried out across Northern Ireland.

Service development needs were costed at the basic level needed to meet framework standards. These exercises covered paediatric, adult and regional

services. They involved appropriate clinical and commissioning representatives from the HSC Board and trusts.

Following the basic costing exercises, an analysis of money allocated within the Health and Wellbeing Investment Plan was carried out against the standards in the Framework. Time frames for standards were altered to allow for differential funding streams. Funding was allocated to trusts in relation to identified priorities.

Whilst all funding provided for years 2008/09 and 2009/10 was allocated to services, RQIA was advised that there was a need to ensure that funding was used in relation to the identified priorities at provider level. Staff interviewed highlighted the need to have clear mechanisms to monitor how funding was being used.

Links to Commissioning

The HSCB and PHA take forward the regional commissioning agenda through a series of integrated, multi-disciplinary service teams. The standards within the framework needed to be mapped into the correct commissioning team and into the existing financial/commissioning structures. For example, the health promotion standards fall under those teams with direct responsibility for this area, while other areas within the framework in relation to specific conditions may fall under a number of the specialist service commissioning teams.

RQIA was advised that the process of ensuring that the framework is taken forward across a number of commissioning teams and the 5 LCGs and that it is therefore challenging to maintain a coherent approach to the overall implementation process.

Change Management

Where there were gaps in the information required to monitor progress against the standards and key performance indicators, the implementation lead considered alternative approaches to glean information about progress.

A process of change management was put in place to enable DHSSPS to agree changes to allow for improved monitoring of the framework.

RQIA found that there was a growing view that there was potential for introducing a more limited set of 'vital signs' to monitor the next version of the framework. There was also a clear need to ensure that there were agreed processes to measure KPI's in the framework.

4.5 Ensuring effective participation

The process to develop service frameworks was specifically designed to ensure that there was wide engagement with relevant organisations, and service users, in the identification of appropriate standards.

During this review, RQIA sought the views of a range of organisations as to the effectiveness of engagement during the implementation process.

RQIA found that, in general, organisations were very positive about the arrangements in place, and their level of involvement. In particular, the personal

contribution of the implementation lead to ensure effective participation was widely welcomed.

Links with the voluntary sector

There are a number voluntary agencies operating within Northern Ireland which have a specific interest in the management of respiratory disease.

- The British Lung Foundation (BLF) provides support and advice to people affected by, or interested in, lung conditions. The Foundation has established a network of several 'Breathe Easy' groups in Northern Ireland. Groups meet monthly to share experiences and listen to guest speakers.

- Northern Ireland Chest Heart and Stroke (NICHS) supports research and provides a network of 25 Respiratory Support Groups across Northern Ireland. The Respiratory Support Groups meet regularly to offer support to people living with respiratory conditions, and their families and carers.

- Asthma UK works across the United Kingdom to improve services for the estimated five million people with asthma. It has a local office in Belfast. The vision of the charity is to live in a world where asthma is no longer a daily battle for some and where no one dies from the condition. The charity supports research, and provides information and services,

- Cystic Fibrosis Trust is a UK charity dealing with all aspects of cystic fibrosis including in Northern Ireland. The charity funds research to improve CF care and treatment, and aims to ensure appropriate clinical care and support for people with cystic fibrosis.

RQIA met with representatives of each organisation. Three of the four organisations advised that they have been kept well informed about the ongoing implementation of the framework through their representation on the Regional Respiratory Forum and individual trust forums. One organisation was not a member of this Forum.

The Regional Respiratory Forum was described as a 'great venue for the transmission of information to and from the HSC' and voluntary agencies described how they are encouraged to contribute, and to provide an update on the work they are progressing.

Agencies welcomed the annual RAG update which provided an overview of all the respiratory standards and the associated key performance indicators. This highlighted where progress was being made, and identified areas where further action was required. The view was expressed that there was a need for a stronger action plan to take forward those areas where more progress was needed.

Agencies advised that they do sometimes encounter difficulties in engagement with HSC organsiations when communicating in relation to difficult decisions. However, this has not been the case in relation to the implementation of the Respiratory Service Framework. Difficult decisions, such as which services to develop, or limitations on funding, are discussed and are always supported by relevant evidence.

RQIA was advised that the regional implementation lead frequently engaged with patient groups to answer questions and discuss the framework. This allowed the lead to hear directly the expectations of patients and to ensure that, through the implementation of the framework, the needs of service users are met.

Voluntary sector organisations informed RQIA that they recognised that there was a lack of administrative and project support available to the implementation lead for the framework.

RQIA found that the framework implementation process was supported by extensive partnership working with voluntary agencies in areas such as self-management, provision of support and the development of information publications.

Examples of initiatives included:

- NICHS self-management course: 'Taking Control'
- BLF self-management course: 'Living with COPD'
- NICHS & Asthma UK patient experience surveys
- NICHS: COPD booklet
- BLF: 'Love your Lungs' screening project
- Asthma UK: 'Alert to Asthma' programme
- Asthma UK: Conference 'Self-Management: A New Partnership'
- Allergy NI information pack

Voluntary agencies reinforced the benefits of joint working between voluntary and statutory services. Services provided by voluntary organisations can offer important support to patients. However, organisations advised that health professionals are not always aware of the services which are available for patients in their area. For example, the uptake of respiratory rehabilitation and support programmes is low in some areas.

Voluntary agencies reported that a particular difficulty for them can be in funding arrangements for the services they provide. While welcoming the provision of one-off funding for particular initiatives, sometimes from end of year monies, they advised that it is very difficult to sustain a service on this basis. They considered that funding for proven initiatives and future collaborations needed to be better planned, and where possible, made recurrent.

Overall RQIA found that voluntary agencies considered that the implementation process has been a success. It has shaped the way services are being taken forward. It has led to people thinking and working differently which has contributed significantly to improvements in respiratory services.

Many of the standards in the framework have been achieved within limited resources. In only a few cases has there been no progress against the standards. There was much praise for the implementation lead in driving the implementation forward and for the recognition which had been given to the voluntary sector for the work that they do.

Challenges which had been identified included: a lack of associated resource to take the framework forward; a lack of support for the implementation lead in terms

of administrative and project support, and a lack of awareness of some of the services and support which the voluntary services provides for patients.

Involvement of HSC organisations

A number of staff across trust organisations and primary care were consulted regarding their involvement in the implementation process.

Staff advised that the framework had brought together earlier individual initiatives and areas of good practice, giving this work a common driver. It created an impetus within the HSC to drive sustained improvement.

The initial standards were developed following engagement with clinical teams and were based around care pathways. The standards were set from the patient perspective and measures of success were set high to encourage improvement. The approach which had been taken was considered to have been useful and appropriate.

When the framework was launched, trust staff from a range of backgrounds came together: to assess the current situation; identify the requirements necessary to meet the standards; begin the implementation process; and plan for future service developments. Groups were formed with representation from primary and secondary care and commissioning bodies.

The Respiratory Service Framework was noted to have raised the profile of some particular clinical conditions and has contributed to achieving mainstream funding for some specific service developments.

One specific achievement, which was considered to be strongly linked to the framework, was that paediatric respiratory services were raised on the commissioning agenda, as an area which required service development for the future. Development was supported by a share of the funding made available for the overall implementation of the framework. This led to several specific developments such as the formation of the Regional Paediatric Respiratory, Allergy And Anaphylaxis Group and the establishment of several specific medical, nursing and allied health professional posts.

When speaking with GPs, some felt that perhaps the implementation has focused primarily on secondary care. They perceived that, although the standards within the framework are good, they are more difficult to implement within the GP community, as there is no hierarchical structure to drive implementation.

GPs provided examples of initiatives designed to improve services for patients with respiratory conditions. Practice nurses can play a significant role in supporting practice level services such as spirometry clinics and smoking cessation clinics.

There has been funding of a Locally Enhanced Service (LES) for Asthma and COPD. This has since been used as a basis for commissioning and the integrated pathway and framework standards are now integrated into the Integrated Care Partnership specification for respiratory disease.

Some GPs considered that the only way to ensure effective implementation of a framework is to convert the standards into targets for enhanced services which will require investment. There is a need for GPs to take the standards within the framework and develop them into pathways for patients.

During discussions with staff from both primary and community care, a common theme was that the care of patients with respiratory disease provides a real opportunity to take forward the plans set out in 'Transforming Your Care' A Review of Health and Social Care in Northern Ireland (December 2011)[11]. The implementation arrangements established for the framework can help to ensure a coordinated approach to moving this agenda forward.

Links with education and research

During the development of the Northern Ireland Strategic Framework for Respiratory Conditions, it was recognised that education providers for health professionals would have important roles in taking forward the goals of the strategy. Links with education were established at that time, and further strengthened by the development and implementation of the Respiratory Service Framework. A series of educational road shows was held across Northern Ireland in relation to Asthma and integrated enhanced self-management within pulmonary rehabilitation programmes.

A Senior Lecturer in Physiotherapy from the University of Ulster sits on the Regional Respiratory Forum. This provides an opportunity to consider the requirements of the framework and to identify and discuss training requirements to support implementation. This can lead to the commissioning of relevant training to ensure that core needs are met.

RQIA found that a range of educational programmes have been established which are of direct relevance to the implementation of the framework:

- A post graduate Certificate in Respiratory Health has been established in collaboration with the University of Ulster. This course aims to promote evidence based care in respiratory health for the benefit of patients and society. It enables the practitioner to develop an in depth understanding of clinical practice, underpinned by knowledge of the appropriate theory and research.

- Nursing staff have worked with Queens University Belfast in the development of a module within the BSc (Hons) in Specialist Practice for Respiratory Nursing. The overall aim is to facilitate the development of specialist practitioners in order to adequately address the challenges identified by the Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006) and the Respiratory Service Framework.

[11] http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf
Transforming Your Care is a major programme involving the Department of Health, Social Services and Public Safety, the Health and Social Care Board and the Public Health Agency, working in partnership with the Health and Social Care Trusts and other service providers. In December 2011 "Transforming Your Care" was published setting out 99 recommendations for the future shape of health and social care services. These recommendations are now taken forward by the DHSSPS, HSCB and the PHA.

- The development of the R-CAT (Respiratory Competency Assessment Tool) was commissioned by DHSSPS and facilitated by NIPEC. The R-CAT was developed during 2008 to assist nurses and midwives build competence in relation to the care and management of patients/clients with asthma and chronic obstructive pulmonary disease. It is based on learning needs arising from the Respiratory Service Framework standards for service delivery in Northern Ireland.

RQIA was also advised that educational support has been provided by the voluntary sector. The Causeway Breathe Easy group funded a 3 year educational programme for 9 respiratory nurses in the Northern Health and Social Care Trust. These nurses will be designated as British Lung Foundation nurses, giving them access to training and support from the British Lung Foundation. In the future, it is hoped to roll this programme out to other HSC trusts.

The need for research to underpin the framework has also been identified. Research undertaken during the development and implementation of the framework has been used to drive improvements in areas such as COPD self-management and the development of the new oxygen contract. During these processes there was considerable engagement with service users.

In addition to this there have been two knowledge transfer schemes, supported by the HSC Research and Development office, were established to help implement the service framework standards.

4.6 Views of service users

Northern Ireland Chest Heart and Stroke (NICHS) and the British Lung Foundation (BLF) provide a network of established support groups across Northern Ireland. These groups provide opportunities to:

- allow people to share experiences
- provide information on living with a respiratory condition
- provide information on healthy lifestyles
- organise social events and outings
- promote continued rehabilitation
- point the way to other services including self-management, respite & befriending service and welfare grants
- provide an opportunity to highlight concerns and advocate on behalf of members.

To inform this review, RQIA engaged with members of several of these groups, and with Asthma UK, to seek user views as to how services had been provided during the period of implementation of the framework.

Awareness of the Framework

Few service users were directly aware of the framework. Most had not seen the easy access version of the document which was designed specifically for service users and their families. The purpose of the easy access version was to summarise the full document, to explain the names of diseases and other specialist terms, and

to explain the roles of the various organisations responsible for taking action on each of the standards.

In one group some service users had been involved in the development of the framework. They were aware of the easy access version and of the background to the framework.

Support & Information

Service users were invited to comment on the information and /or support they, or their families, had received. Information had been provided verbally from a number of sources including practice nurses within local GP surgeries, and from the teams of respiratory nurses in the trusts.

Many service users felt that support groups were a very valuable source of up to date information about their specific conditions, health promotion and practical support such as welfare issues.

Views expressed about information and support were generally positive. Some service users thought that there had been a lack of information given at the time of investigations and diagnosis, and a lack of support for both the patient or for their carer.

Treatment and Care

Service users were asked to comment on the treatment and care they received. Many expressed very positive comments about specific services.

Some patients described perceived delays in being referred by GPs to hospital services. One felt that a delay in referral meant that the symptoms may have improved so the hospital staff don't always see the true picture when their condition is at its worst.

Some expressed concerns about the arrangements for review and check-ups. In particular, concerns were raised about the involvement of GP locums, who patients felt were not fully aware of their individual circumstances.

Patients who had been referred into the acute hospital system they felt their care tended to improve and they reported having regular reviews. Patients who had been admitted to hospital described how they were followed up by the GP after discharge. This gave an opportunity to assess their condition and to reassess treatment and medications.

Patients provided examples of how respiratory services had significantly improved their quality of life. For example, one service user described how respiratory team staff had helped him to come to terms with his condition. He described how staff had been honest and forthcoming, positive but realistic. He had been offered pulmonary rehabilitation and found this to be very helpful, continuing with the exercises at home. He had been provided with oxygen therapy and described how this is delivered directly to his home. This means he can manage his own oxygen supply, which has gone a helped him maintain his independence.

Self-Management

Service users were asked how they were helped to understand their symptoms and how they could identify if their symptoms were getting worse, so they could self-manage their conditions, when possible.

Most group members recalled being provided with a self-management plan, usually in a written form, shortly after they had received their initial diagnosis. They were confident that they could recognise when their symptoms were worsening and what actions they should take. Some patients had been able to manage symptoms in their own home and therefore did not need to be admitted into hospital.

Several service users described their involvement on the 'Tele-monitoring NI' initiative. This allows the patient to have daily checks of their blood pressure, temperature and oxygen levels in their own home. This information is them transmitted via the tele-monitoring equipment and is recorded centrally. If required, the patient will receive a telephone call to check on them. This system allows for early identification of medical problems such as the onset of a chest infection and in turn allows for early intervention. Patients involved in this initiative were very positive about the support it provided.

Some service users had attended the NICHS 6 week self-management course 'Managing the Challenge'. These courses were usually held locally. Others had attended the BLF 6 week 'Living with COPD' course. They became aware of these courses either directly through support groups or via information provided by practice nurses. In addition to advice specific to their conditions, some recalled being given additional advice on diet modification.

Generic Medication

Service users expressed some concerns about the provision of generic drugs. They described feeling confused when they are given the same drug but it looks different or is a different strength from the usual version received. Some perceived that although they recognised that the formula may be the same, they personally felt the effect on their symptoms was different.

Use of Equipment

All service users who used equipment such as inhalers, nebulisers or oxygen therapy advised that they had been shown how to use it either by the practice nurse or by the respiratory team. Some patients expressed concern that the HSC will not provide nebulisers and that the patient has to buy this equipment themselves.

Some support groups provide refresher courses in equipment use and there is also regular support and advice from the respiratory team and/or practice nurses. Generally those spoken to felt there was good on-going support and advice in relation to equipment.

Smoking Cessation

Members of all groups indicated that they were given advice to stop smoking and were referred onwards to smoking cessation services. Many of the members said they had been able to quit with this support.

Support Groups

Service users described the benefit provided by the support groups they had attended. It was noted that the support groups are open to all, including carers.

While some were told about support groups via their GP, practice nurse or respiratory teams, others had to source information themselves. Some had heard about the groups via newspaper articles or promotional events.

Members of the groups described how they provided advice and support around many practical issues such as welfare rights. The groups also provide information on respiratory conditions, smoking cessation advice, services such as rehabilitation classes and refresher classes, in areas such as inhaler techniques.

It was recognised that being a member of a support group is good for some people but not all people like the idea of attending such groups. Those who did attend the groups felt the support provided was invaluable and meant they didn't feel alone. Groups provided opportunities to share experiences, to learn from others and also provided opportunities for socialising.

Overall, service users felt that their treatment and care was excellent, considering that the HSC is operating within limited resources. Service users felt that respiratory nurses provide an excellent service even though they have other job commitments. Some service users felt that when a GP surgery has no practice nurse, this is a weakness, as there is a lack of appropriate support and advice.

Patients felt that voluntary agencies are supplementing the HSC services they receive; there was a general feeling that this should be acknowledged.

Service users described their on-going management as good. Information was clear and all health professionals involved in their care were generally saying the same things so they were not confused about their condition or its management.

4.7 Emerging outcomes from the framework

Many of those interviewed by RQIA were very positive about the impact of both the framework and the earlier work on the Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006).

The service framework was described as a tool which had set out agreed areas for improvement. Endorsement by the Minister was considered to provide the approval required to progress the standards, rather than them being regarded as aspirational.

RQIA was advised that the process of implementation of the Respiratory Service Framework had facilitated the development of a number of specific initiatives to improve services for patients.

Long Term Oxygen Therapy (LTOT) Contract

Through service user engagement, it was established that the oxygen contract in place in Northern Ireland was more restrictive than arrangements in place in other parts of the United Kingdom. Patients in Northern Ireland had poorer access to a range of modalities of oxygen, including items such portable equipment. These restrictions were impacting on patients' quality of life and their level of independence.

A decision was taken to review the existing oxygen contract. This work was led by the HSC Board and included significant engagement with patients and service providers to confirm what a new contract should deliver. A new contract, which now meets the needs of both the patients and professionals, came into effect on 1 January 2013. Funding is now being made available to support the Home Oxygen Service Assessment and Review (HOSAR) service.

RQIA was advised that the revision of the oxygen contract has been an example of 'invest to save' as there are now more efficient and appropriate ways to provide oxygen when required for the patient. The cost of re-imbursement of electricity has also reduced, as the new equipment is more energy efficient.

Asthma and COPD Supporting Tools for the Implementation of National Guidance

The Regional Respiratory Medicines Advisory Group established project groups to develop tools to support practitioners in the selection, initiation, monitoring, review and cessation of pharmacological treatments for the management of both asthma and COPD in line with national guidance.

Throughout their development, the draft documents were reviewed and revised, through consultation with the wider HSC in Northern Ireland, voluntary organisations and the pharmaceutical industry. They were developed in line with relevant national guidelines.

The aim is to ensure that prescribing in line with the document will not only improve the quality and safety of treatments being provided to patients, but also ensure appropriate use of healthcare resources.

Following the development of supporting tools for the Implementation of National Guidance, the Regional Respiratory Medicines Advisory Group continued to develop self-management plans for patients with respiratory conditions. Prior to this a number of different tools had been available.

The collaborative approach used by the group allowed for the development of a standardised tool that was readily available to all, rather than individual practitioners having to seek out a tool and then adapt it to fit their purposes.

The Regional Paediatric Respiratory, Allergy And Anaphylaxis Group has led on the development of an anaphylaxis care pathway which is now standardised across all

trusts. Trusts are currently at different stages of implementation. The group has also developed paediatric information leaflets and self-management action plans. The group has now commenced work to develop a standardised care pathway for asthma.

Enhanced Pharmacy Role

The Regional Respiratory Medicines Advisory Group has been working to develop an enhanced role for community pharmacy in education in inhaler techniques. The HSCB has developed a 'Managing your Medicines' scheme through community pharmacies, which allowed pharmacists to monitor patients' use of inhalers to ensure they are being used appropriately.

A patient can be referred by their physician or can self-refer to the pharmacist for a review of their technique. In addition, a pharmacist can suggest a review based on individuals patient's usage statistics. This initiative was generally cost neutrall, as it was funded by changes in the pharmacy contract.

Community Palliative Care Information System

In relation to palliative care information, a group was set up to develop measurement systems. This group used existing community systems to measure framework standards. This group also developed an operational checklist for all conditions with palliative care needs. This has now been implemented in all Trust areas.

Additional Service Developments

RQIA was advised that a number of further service developments have been taken forward in relation to the framework as it continues to be rolled out.

- There has been funding of a Locally Enhanced Service for Asthma and COPD. This has been used as a basis for commissioning and has since been integrated into commissioning plans for 2011/12 and 2012/13.
- 2.5 Whole Time equivalent (WTE) nurse posts have been funded for regional Tuberculosis services.
- Over £400,000 has been made available for paediatric nursing and dietetics.
- £170,000 has been made available to start an Obstructive Sleep Apnoea (OSA) service in the Northern Health and Social Care Trust area.
- The integrated COPD care pathway, which was developed as part of the framework standards, has been used as the basis for Transforming Your Care (TYC) and the Integrated Care Partnerships (ICP) specification for respiratory conditions.

5. Conclusions

5.1 Context

The process to develop service frameworks for health and social care in Northern Ireland was initiated in 2007. The framework for respiratory disease services was launched in November 2009. This review was established to consider the arrangements for implementation, over the three-year period to 2012.

The framework was launched at a time when the organisational and financial context was changing significantly. In 2009, a new HSC organisational structure was established with the formation of the HSCB and the PHA. Between 2009 and 2012, the financial environment in which the framework was being implemented changed significantly. The availability of planned funding did not fully materialise.

Against this background, RQIA has concluded that an active process for implementation of the framework continued throughout the period 2009 to 2012, leading to improvements in the design and delivery of services for patients.

The wider context continues to evolve and the framework is now being reviewed. In 2012, the Transforming Your Care (TYC) strategic initiative was established. The arrangements established to implement the framework provide a strong platform to take forward the TYC agenda, to ensure continuing improvement in respiratory services.

5.2 Support for the framework

During this review, RQIA found strong support for the framework process across individuals and organisations. The concept of a framework, setting out commonly agreed standards, is widely accepted and supported. The standards established for the framework in 2009 were considered to have been appropriate although, some have proved difficult to measure.

There was a general consensus that the framework had facilitated service improvement and development during the implementation period. There was a strongly held view that the momentum generated by the framework needed to be maintained.

5.3 Role of the implementation lead

When the development of a programme of service frameworks commenced the DHSSPS, HSCB and PHA identified a public health consultant as the lead for both organisations for the development of the Respiratory Service Framework. This responsibility subsequently passed to a second public health consultant who was subsequently responsible for leading the implementation of the framework.

Many stakeholders expressed the view that the role of the implementation lead had been critical in delivering the benefits in partnership working and service improvement which had taken place during implementation of the framework.

Concerns were expressed that, while there had been some project and administrative support for the implementation lead made available for various aspects throughout the development and implementation period, this was on an ad-hoc basis. In addition to this there appeared to be a lack of succession planning which could cause difficulties if the lead was to leave this area of work.

RQIA has concluded that there is a need for a defined implementation lead to take forward each service framework, who has the authority, time and appropriate support to enable this key role to be effectively delivered.

It is recommended that the identified regional lead to take forward the implementation of each service framework is provided with appropriate administrative and project support to carry out this role effectively.

5.4 Implementation structures

During the process of implementation of the Respiratory Service Framework, the implementation structures evolved as a result of experience and in order to address emerging challenges. This flexible approach worked effectively and provided opportunities for service development to be taken forward.

Following this review and its previous review, of the implementation of the Cardiovascular Disease Service Framework, RQIA has concluded that there is no single, best, implementation structure for a service framework. For each new framework an implementation structure should be designed. This should be kept under review as the implementation process moves forward.

From the findings of this review, factors which contributed to the success of the implementation process included:

- The role of the Regional Respiratory Forum as an overarching group, to own the overall implementation process, and to provide a mechanism through which the large number of stakeholders could come together to agree on the way forward,
- The development of specific subgroups to take forward particular areas of work with reporting mechanisms to the forum.
- The development of a set of service specifications for respiratory disease which facilitated links between the framework and the implementation, and commissioning processes.

In view of this experience RQIA recommends that future service frameworks should adopt the following processes in relation to implementation arrangements:

For each service framework, an existing regional network or forum should be identified, or a new stakeholder group established to support the implementation process.

For each service framework, consideration should be given to the development of a set of service specifications to facilitate the translation of the framework standards into the commissioning arrangements for services.

5.5 Monitoring arrangements

Monitoring of the Respiratory Service Framework included consideration of each of the individual standards of the framework. Development of the set of service specifications was found to facilitate the monitoring process.

RQIA has concluded that the annual RAG progress report, developed by the implementation lead, was a key document in ensuring that progress was reviewed against the whole framework. A range of sources of information were used to enable monitoring of many of the standards. However, there were a small number of standards where progress could not be measured due to the unavailability of accessible data.

The development of the monitoring arrangements helped to ensure that all those involved had a common understanding as to the level of progress which had been achieved. However, there were no agreed high level indicators for overall progress in tackling respiratory diseases set out in the framework.

In England there is a move towards a vital signs approach to monitor overall progress of framework outcomes. This involves selecting a small number of indicators which are regularly monitored and the results disseminated. The development of such an approach was previously recommended by RQIA in its review of the implementation of the Cardiovascular Disease Service Framework and is supported by this further review.

It is recommended that, for each service framework, a small number of high level indicators should be selected for assessing progress towards the overall goals of the framework.

RQIA has been advised that work is ongoing by HSCB and PHA to develop a common approach to monitoring across frameworks. Standardisation of arrangements for the development and presentation of frameworks has been very beneficial in facilitating the overall framework initiative. Developing a standard approach will support the overall monitoring arrangements for frameworks.

It is recommended that the development of a standard approach to the monitoring of frameworks is developed and implemented.

5.6 Change Management

During the period of implementation of a service framework, it is inevitable that there will be changes which will impact on the implementation process. There are likely to be new developments in treatment and diagnosis. New sources of information may become available. New guidelines and standards may be published. The wider context in which the framework was developed may evolve in response to service strategies, or financial pressures.

RQIA was provided with evidence that all of these types of change were experienced during the implementation of the service framework.

A process was established to consider the implications of relevant changes and, where appropriate, to bring them to the attention of the DHSSPS in the form of a change paper. Proposed amendments to the framework were then considered and subsequently decided on by the programme board. This approach worked well for all of the parties involved and allowed for the measurement of alternative indicators to be undertaken. The process as described is now common across all frameworks and has been formalised in a letter from the Chief Medical Officer to the HSC dated 22 December 2011.

5.7 Involvement with stakeholders

The review team found that collaboration with service users, stakeholders and the public was well planned and to the forefront of both the development and the implementation of the Respiratory Service Framework.

The implementation arrangements for the framework provided a networked implementation structure, with significant contribution from voluntary agencies. The framework structure brought together people from many differing backgrounds. RQIA observed that the benefits of this collaboration were clearly demonstrated throughout the implementation process.

Voluntary agencies strongly supported the engagement arrangements established for this framework. However, they did express concern about the funding arrangements for specific service initiatives which they had put in place. Difficulties arise when a service is only funded on a short term basis in relation to sustaining a viable service. Agencies also advised that some of the support services which have been put in place are not fully utilised by statutory services.

It is recommended that the arrangements for disseminating information about the range of both voluntary and statutory services are reviewed, to ensure that referring practitioners have a clear understanding about the services available in their area.

6. Recommendations

Recommendation 1: The identified regional lead to take forward the implementation of each service framework should be provided with appropriate administrative and project support to carry out this role effectively.

Recommendation 2: For each service framework, an existing regional network or forum should be identified, or a new stakeholder group established to support the implementation process.

Recommendation 3: For each service framework, consideration should be given to the development of a set of service specifications to facilitate the translation of the framework standards into the commissioning arrangements for services.

Recommendation 4: For each service framework, a small number of high level indicators should be selected for assessing progress towards the overall goals of the framework

Recommendation 5: The development of a standard approach to the monitoring of frameworks is developed and implemented.

Recommendation 6: The arrangements for disseminating information about the range of both voluntary and statutory services are reviewed, to ensure that referring practitioners have a clear understanding about the services available in their area.

Appendix A: The Standards in the Service Framework for Respiratory Health and Wellbeing

COMMUNICATION WITH PATIENTS, CLIENTS AND CARERS

Standard 1
All patients, clients and carers should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care

Standard 2
All patients, carers and the public should have opportunities to engage actively and meaningfully with HSC organisations at all levels

Standard 3
Health and social care should work in cooperation with voluntary, education, youth and community organisations to prevent the recruitment of young people to smoking

Standard 4
All relevant health and social care professionals should identify people who smoke, make them aware of the dangers of smoking, advise them to stop and provide information and signposting to specialist cessation services

Standard 5
All relevant health and social care professionals should identify inactive[12] individuals and, where appropriate, provide them with advice and support to accumulate a minimum of 30 minutes of moderate activity[13] on 5 days of the week or more

Standard 6
Health and social care should work with early year's settings, schools, workplaces and communities in the promotion and support of breastfeeding, healthy eating and physical activity to prevent obesity

Standard 7
All individuals should be up to date with their personal vaccine schedule

CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

Standard 8
All people suspected of having COPD should have accurate diagnosis, assessment and management in primary care

Standard 9
All patients with severe COPD should have access to specialist respiratory team care in the community

[12] inactive refers to all people who do not meet the recommended level of physical activity
[13] e.g. walking briskly, walking downstairs, dancing, biking, swimming, gardening, housework e.g. washing floors

Standard 10
All patients with COPD and their carers should be given the opportunity to learn about their disease and receive self-management information

Standard 11
All patients with COPD, who are hypoxic (low oxygen), should have referral for assessment and prescription for long term oxygen therapy, if appropriate

Standard 12
All patients with COPD should be treated with appropriate controlled oxygen therapy during transportation in ambulances

Standard 13
All patients with an acute exacerbation of COPD should be managed to an optimal standard in an appropriate setting

Standard 14
All patients with COPD with acute and/or chronic type 2 respiratory failure should have timely access to ventilator support, if required, in a unit supervised by a respiratory physician or intensive care physician

Standard 15
All patients admitted to hospital with acute exacerbations of COPD should be assessed and, if appropriate, managed at home

ASTHMA IN ADULTS

Standard 16
All people with suspected asthma should have an appropriate assessment and investigations to confirm the diagnosis

Standard 17
All patients with asthma and their carers should be given the opportunity to learn about their condition and receive self-management information

Standard 18
All patients with asthma should be on appropriate pharmacological therapy according to the nature and severity of their disease

Standard 19
All patients with acute severe asthma should be accurately assessed and managed appropriately according to the severity of their presentation

Standard 20
All patients with 'difficult asthma'[14] should be assessed and managed by a team with the appropriate skills and experience

[14] 'Difficult asthma' is defined as those who are symptomatic on BTS/SIGN

ASTHMA IN CHILDREN AND YOUNG PEOPLE

Standard 21
All children and young people in whom there is a clinical suspicion of asthma should have an accurate assessment and access to diagnostic tests

Standard 22
All children and young people diagnosed with asthma should receive individualised evidence based management

Standard 23
All children and young people with asthma who have an acute exacerbation should receive a timely high quality assessment of severity and evidence based management and review

Standard 24
No child or young person should have a second unmanaged anaphylactic event

Standard 25
All children and young people with asthma should be managed according to evidence based guidelines

COMMUNITY ACQUIRED PNEUMONIA IN ADULTS

Standard 26
All patients with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to BTS pneumonia guidelines

COMMUNITY ACQUIRED PNEUMONIA IN CHILDREN AND YOUNG PEOPLE

Standard 27
All children and young people with suspected community acquired pneumonia (CAP) should be assessed, diagnosed and treated according to the BTS guidelines

OBSTRUCTIVE SLEEP APNOEA/HYPOPNOEA SYNDROME (OSAHS) IN ADULTS

Standard 28
All adults with a clinical suspicion of having obstructive sleep apnoea/ hypopnoea syndrome (OSAHS) should have investigation at a specialist OSAHS service led by a respiratory physician

Standard 29
All patients with more complex obstructive sleep apnoea disorders should have timely and appropriate access to attended polysomnography (PSG)

Standard 30
All patients with OSAHS should be provided with information on lifestyle modification and referred to services as appropriate

Standard 31
All patients should have timely and equitable access to CPAP treatment, review and follow up at HSC Trust level. Patients who are unable to tolerate CPAP should have access to assessment for suitability for an intra-oral device

OBSTRUCTIVE SLEEP APNOEA SYNDROME IN CHILDREN AND YOUNG PEOPLE

Standard 32
All children and young people with obstructive sleep apnoea syndrome (OSAS) should have the condition accurately assessed for severity and treated in a timely fashion

LONG TERM VENTILATION IN CHILDREN AND YOUNG PEOPLE

Standard 33
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

CYSTIC FIBROSIS

Standard 34
All babies born in Northern Ireland should be screened for cystic fibrosis

Standard 35
All people suspected of having cystic fibrosis should have appropriate diagnostic testing at a specialist centre

Standard 36
All patients with cystic fibrosis should receive care as per guidelines via specialist multidisciplinary teams

Standard 37
All patients with cystic fibrosis should have their care provided in a safe environment consistent with infection control policies

BRONCHIECTASIS

Standard 38
All people (children and young people and adults) with suspected bronchiectasis should have an appropriate diagnostic assessment

Standard 39
All patients with symptomatic bronchiectasis should be accurately assessed and managed by the specialist respiratory team

Standard 40
All patients with symptomatic bronchiectasis and their carers should be given the opportunity to learn about their disease and receive self-management information

TUBERCULOSIS

Standard 41
All people considered to be at high risk of tuberculosis (TB) should be able to access services for screening and BCG vaccination as appropriate

Standard 42
All patients with active tuberculosis who require admission to hospital should be managed in hospital according to strict infection control standards

Standard 43
All patients with active tuberculosis should have appropriate individualised management

Standard 44
All patients with active tuberculosis, and their contacts, should be managed by professionals with appropriate skills and experience

INTERSTITIAL LUNG DISEASE (ILD)

Standard 45
All patients with ILD or suspected ILD should be under the care of a respiratory physician with appropriate clinical, physiological, radiological, pathological, surgical and laboratory support

NEBULISER TREATMENT

Standard 46
All patients with respiratory disease should only start long term home nebuliser therapy following appropriate assessment and education

PULMONARY REHABILITATION

Standard 47
All appropriate patients with respiratory conditions and symptomatic breathlessness should be offered referral to pulmonary rehabilitation

TRANSITIONAL CARE FOR ADOLESCENTS WITH CHRONIC RESPIRATORY DISEASE

Standard 48
All young people with chronic respiratory disease (asthma / OSAS / LTV / cystic fibrosis / bronchiectasis) should have appropriate arrangements in place for transition and transfer to adult services

LUNG TRANSPLANTATION

Standard 49
All patients with respiratory disease, who meet the criteria for lung transplantation, should have the opportunity for referral to a transplant centre

ACUTE OXYGEN THERAPY

Standard 50
All acutely ill patients, apart from those at risk from hypercapnic respiratory failure, should have oxygen prescribed to achieve a normal or near normal oxygen saturation

SOCIAL AND EMOTIONAL SUPPORT

Standard 51
All patients with severe respiratory disease and their carers should be offered a 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

INFORMATION

Standard 52
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

PALLIATIVE CARE

Standard 53
Health and social care professionals, in consultation with the patient, should identify, assess and communicate the unique supportive, palliative and end of life care needs of that person, their caregiver/s and family

Standard 54
All patients, carers and families should have access to responsive, integrated services which are coordinated by an identified team member according to an agreed plan of care, based on their needs

Standard 55
All people with advanced progressive conditions, their caregivers and families, will be informed about the choices available to them, by an identified team member, and have their dignity protected through the management of symptoms and maximising comfort in end of life care

Appendix B: Chronology Overview

DATE	EVENT/ACTION
March 2006	Northern Ireland Strategic Framework for Respiratory Conditions ('A Healthier Future': March 2006) is published.
1 March 2007	Letter from the Chief Medical Officer and Deputy Secretary DHSSPS to HSC organisations announcing the establishment of a programme to develop service frameworks.
23 April 2007	Correspondence from the DHSSPS enclosing a standardised template for the development of frameworks which was issued to ensure consistency of approach across all the frameworks to be developed.
November 2009	The Respiratory Service Framework is formally launched by Michael McGimpsey, MLA, then Minister for Health, Social Services and Public Safety.
25 November 2009	Letter from DHSSPS to HSC Board and PHA, copied to trust Chief Executives, regarding the Service Framework for Respiratory Health and Wellbeing. This letter requested that the HSC Board and the PHA to : • develop a plan for the phased implementation of the Respiratory Service Framework, • Identify a senior professional to lead the implementation process, • submit a jointly agreed plan by 31January 2010 for the phased implementation of the framework by March 2012, • provide assurance to the DHSSPS in relation to the achievement of the framework standards on a six monthly basis. This letter also stated that the Respiratory Service Framework would be underpinned by a significant investment of £6.5 million an additional £3.2 million in general medical services for the treatment of COPD and asthma.
January 2010	Assessment of Asthma: An Audit of attendance at A&E and Out of Hours Services, based on SIGN/BTS guidelines, commences. The aim of the audit was to assess A&E services and GP

	out of hours and follow-up services for people (adults and children) with an exacerbation of asthma (acute severe) in line with the management of asthma outlined in the SIGN/BTS guidelines (Appendix 2 and 4) and standards set out in the Northern Ireland Service Framework for Respiratory Health and Wellbeing (Appendix 3); and to make appropriate recommendations for service development/standards based on the results of the audit.
March 2010	A detailed implementation plan for the framework including an implementation schedule was produced and subsequently updated in October 2010.
24 March 2010	A series of Service Specifications are drafted for Adult Respiratory Services and tabled alongside the implementation plan at a workshop attended by representatives from trusts, Primary Care, HSCB and PHA. A similar process was underway for Paediatric respiratory services with a workshop planned for June 28th 2010.
4 May 2010	Letter from PHA to the Trust Respiratory Forum Leads regarding feedback on the service specifications for the Respiratory Service Framework. This letter asked trust lead to liaise with their respiratory forum and colleagues to coordinate feedback on each of the Adult Service Specifications. In particular the leads were asked to consider if any of the service specifications had any gaps or inaccuracies or if they were unachievable. In relation to suggested measurements, it was also requested if they could identify other potential sources of information which were not currently listed. This letter also referenced further correspondence from Director of Performance Management and Service Improvement to trust Directors of Performance Management to ensure that all appropriate trust staff are aware of the requirements to report on implementation of the Service Framework. The letter indicated that apart from generic health promotion and PPI standards, no reports were required until 2011. However, it advised that planning needed to start immediately as measurement will be based on performance during 2010/11.
17 April 2011	Letter to implementation lead from the Director of Safety, Quality and Standards, DHSSPS. This letter confirmed accepted changes to the Service Framework for Respiratory Health and Wellbeing. These changes were

	agreed under the draft review mechanism for changes considered necessary during the life cycle of a framework.
April 2011	Following its first year of implementation, version 2 of the Respiratory Service Framework is published. This included a number of suggested changes to the KPIs within the framework. These changes were endorsed by the Programme Board. All the framework documents were updated with the exception of the Easy Access Version.
26 July 2011	The 'Perceptive Insight' report is launched. This is a joint collaboration between the PHA and Asthma UK assessing the progress against asthma standards 17 and 52 within the Service Framework for Respiratory Health and Wellbeing.
22 December 2011	Letter from the Chief Medical Officer stating that accountability for the implementation of all service frameworks had been strengthened. The DHSSPS will now ask for assurance to be given at the regular accountability meetings (twice yearly). It will now be for the HSC Board/PHA also to secure assurance on progress made from individual trusts and other service providers where relevant. This letter further states that RQIA is currently undertaking its appraisal of the implementation of the Service Framework for Respiratory Health and Wellbeing. The framework was due for fundamental review in 2013-14 and the RQIA report would contribute to this.
2 May 2012	Two supporting tools for the implementation of national guidance in relation to Asthma and COPD are launched. During development the draft documents were reviewed and revised through a consultation with the wider HSC in Northern Ireland, the pharmaceutical industry and patient groups such as Asthma UK, the British Lung Foundation and Chest, Heart and Stroke.
11 June 2012	Revised generic standards for inclusion in all service frameworks were launched for public consultation by the Minister for Health in Northern Ireland. Following an evaluation and review of the current generic standards, several proposed amendments had been made. New standards were proposed in areas such as carers, community development and person-centred care, independent advocacy and safeguarding. These additional standards reflected further priority areas for the

	Department and their inclusion as generic standards was designed to raise the profile of these important issues.
23 August 2012	Service Framework Progress Report outlines the progress made in respect of framework implementation. Key Achievements include: • The new regional contact for home oxygen has gone out for procurement. • The spirometry training package for practice nurses to be piloted and five people are to be trained as trainers. • Self-management action plans for COPD, Asthma and Bronchiectasis have been developed. • They have been sent to trusts and will be sent out Accompanying healthcare guidance and anticipatory care planning guidance for exacerbations of COPD. • Community palliative care information systems are now available in four trusts. • A care pathway has been developed for paediatric anaphylaxis management in A&E. • Recommendations have been developed based on the regional audit of management of asthma in A&E and GP out of hours. • Application made for funding from GAIN for the regional bronchiectasis audit. • A regional paediatric asthma action plan and information leaflet is being printed. The report also detailed the key priorities for action over the next 6 months and an assessment of those issues/KPIs which have not progressed.
13 September 2012	The HSC Board and Public Health Agency publish their joint commissioning plan for 2012/13. This sets out the health and social care services to be commissioned and the associated costs of delivery.
7 November 2012	Asthma Self-Management: A New Partnership conference is held in the Lagan Valley island Centre. The aim of the conference was to improve the understanding of self-management and how it can be successfully used in the management of asthma. This collaborative piece of work, funded by the Public Health Agency, was organised and facilitated by Asthma UK.
1 January 2013	New Long Term Oxygen Therapy Contract begins accompanied by a new BSO process for prescribing of

	Long term oxygen therapy or Ambulatory oxygen therapy by HSC Trusts.
9 May 2013	RQIA commences a review focused on reviewing the overall process of implementation of the Respiratory Service Framework as outlined in a letter from the Chief Medical Officer dated 22 December 2011. The findings of the review will inform the process for the implementation of future and existing service frameworks.
14 May 2013	Implementation lead presents an update on the Respiratory Service Framework at the Respiratory Educational Spring Meeting: Building an Integrated Respiratory Service
May 2013	Service Framework Progress Report outlines the progress made in respect of framework implementation. Key Achievements include: • A new regional contract has started for oxygen equipment. This will provide effective and efficient oxygen equipment for patients, a major recognised gap in services. Training to support this has been carried out. Guidelines for use of oxygen have been developed. • The spirometry training package has been developed and piloted. Spirometry training has started to be rolled out. • COPD and asthma management guidance has been developed and sent out to all GPs across Northern Ireland. Training has been provided in each trust area on asthma. • A strategic group is developing a Key Information System for complex and palliative care conditions to support identification, planning and information transfer. • Specifications for COPD for Integrated Care Partnerships, based on standards in the Respiratory Framework have been developed. • Audit results are available regionally for COPD and Community Acquired Pneumonia (CAP) and have been shared with other commissioning teams etc. to achieve improvement. • GAIN funding has been granted for Bronchiectasis. • A care pathway for regional paediatric A&E anaphylaxis (NICE guidance) is being implemented. • A regional paediatric asthma action plan and information leaflet has been developed and sent out to all GP practices and secondary care

	services. • Developments are progressing to set up Obstructive Sleep Apnoea Hypopnoea Syndrome (OSAHS) in NHSCT areas (relieving major waiting lists in BHSCT area). • Quality standards have been set within commissioning for COPD within hospital and community services, based on the COPD care pathway and service framework standards. • A service specification has been developed for the management of asthma in schools. • A regional group has been set up to consider service issues and guidelines in relation to community NIV. • GAIN funding has been obtained to set up a Northern Ireland system to take part in the UK National Review of Asthma Deaths. • A Medicines-Use Review Service is being developed in community pharmacy for COPD and asthma. • Funding has been obtained to further develop the Specialist Respiratory Tuberculosis nursing service in two Trusts and is progressing in one other trust. • One session per week of project support has been allocated recently to implementation of the Respiratory Framework. The report also detailed the key priorities for action over the next 6 months and an assessment of those issues/KPIs which have not progressed.
13 August 2013	RQIA held a stakeholder summit workshop as part of the validation process for the Review of the Implementation of the Respiratory Service Framework.

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