National COPD Audit Programme: Patient Reported Experience Measures (PREMs) Development Work & Feasibility Report

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Introduction

Patient Reported Experience Measures (PREMs) are a key feature on the Government healthcare agenda. PREMs can provide important evidence regarding clinical care from the patient perspective. In conjunction with organisational and clinical audit data, they provide a rounded view of a patient's care experience and support the development of quality improvements.

As part of the national COPD audit programme, one year of development work for the future incorporation of PREMs into the audit programme was commissioned; to inform decisions regarding future roll-out of this element and associated funding.

Patient Perspectives: Background/Current Landscape

There is high level and widespread agreement that patient-centred care sits at the heart of healthcare services. Listening to, and acting on, patients' views are essential to providing such a patient-centred health service and the measurement of patients' perspective of health services and care has become a core element of health policy in the UK.

National health policy in England identifies patient experience as an equal component of health services quality alongside clinical effectiveness and safety (e.g. Darzi, 2008a, 2008b), with priorities focussing on 'Putting Patients First' (NHS England, 2013). The challenge to the system has been how best to measure patients' experience of health services and care.

Patient perspectives on care can be measured in a number of ways.

- **Patient Satisfaction**
  - **Surveys:**
  - **National** - The NHS patient survey programme systematically gathers the views of patients on the care they have recently received using a range of health care services provided by the NHS. The programme enables healthcare regulators, such as the Care Quality Commission (CQC), and others to build up a national picture of people's experience.

    Patients are asked specific factual questions about what happened to them during their recent healthcare experience. Once results are received, each healthcare organisation is encouraged to share and make use of the findings in order to improve their services locally. The results are also used in a range of ways, including the assessment of NHS performance as well as in regulatory activities such as registration, monitoring ongoing compliance and reviews.

  - **Local** - Healthcare organisations also frequently undertake their own local patient surveys. An online survey of Trusts in England looked at current practices among Trusts collecting and using patient experience data and showed a broad variation in methods employed to collect patient data at a local level.

- **PROMs** - Patient Reported Outcome Measures (PROMs) measure quality from the patient perspective. Typically, short, self-completed questionnaires, which measure the patients' health status or health-related quality of life at a single point in time. The information collected from patients via PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to patients.

  The national PROMs programme is NHS England led and uses a number of accredited suppliers to support delivery of the programme. The PROMs programme is limited to England however; a small

number of patients from Scotland and Wales will be included in the national analysis having being treated by English providers.

PROMs calculate the health gain after surgical treatment through the completion of pre and post-operative surveys. Eg A hip replacement questionnaire compares a patient's own assessment of their mobility and pain before and after a hip operation, thus creating a measure of clinical success.

- **PREMs** - Patient reported experience measures (PREMs) can provide valuable information from the patients' perspective on their care. Rather than giving subjective ratings of satisfaction, PREMs focus on asking people to report whether specific events occurred during their care; this approach provides more readily interpretable and actionable data (eg Cleary 1998, 1999). Similarly, PREMs focus on people's lived experiences of care and treatment, rather than the effectiveness of interventions.

  Typically, patient experience surveys seek to measure the issues of greatest importance to the majority of patients (Graham & Woods, 2013). In considering a condition specific PREM, decisions about content should therefore be driven – at least in part – by evidence from patients on what matters to them.

Experience from other national audits - A number of other national audits have already explored various aspects of collecting PREM data and are outlined in detail in section 2.

Feasibility Pilot study

A pilot study was undertaken exploring the feasibility and practicalities of adding 'patient reported experience measures' (PREMs) into the national COPD audit programme. Delivery of the study was managed by the British Lung Foundation, working with the Picker Institute Europe. It considered a range of approaches to measuring people's experiences of COPD in three key settings: primary care, secondary care, and pulmonary rehabilitation (PR).

- **PREM Tool (Questionnaire)** - The project focussed on testing methods and assessing the feasibility of collecting PREMs. In the absence of any existing validated COPD specific PREM tools, the project aimed to use a generic tool, or tools, for piloting. A literature review identified a number of potential generic questionnaires and these were tested with patients via focus groups to ensure their broad suitability and to assess the extent to which tailoring across and within settings would be necessary.

- **Data Collection** - The PREM pilot employed three methodologies:
  - Method one – paper survey, sent via post
  - Method two – paper survey, handed out at the point of care
  - Method three – online survey, distributed via postcard at the point of care.

  Each methodology was tested in the three settings – primary care, secondary care and pulmonary rehabilitation (a three-by-three nested design).

  The characteristics of each method were assessed against three criteria: their practical feasibility, the level of data provided, and the likely costs and cost efficiencies for a national rollout. Collectively these factors provide a rounded overview of the feasibility of adding PREMs into the national COPD audit programme.

- **Findings** - There was a consistent pattern of responses across all three settings. Postal survey responses were highest (51.1% overall), followed by paper hand-out (25%) and online (4.7%).

Developing and rolling out the pilot highlighted a range of challenges and barriers associated with using a PREM tool in support of a COPD audit – some were setting or method specific but the majority were applicable across all three settings. Proposed data collection tool(s) and methodology will need to address these if the benefits of collecting COPD PREMs are to be realised.

- **Summary of Key Lessons Learned**
  - Relatively little work has looked specifically at the requirements of people with COPD or at how people's COPD specific experiences should be measured.
  - In planning and conducting the pilot survey, many key findings and learning points related to the practicalities of getting the survey to the patient; these are not trivial when considering the potential integration of PREMs to a national audit programme.
  - The use of an online survey approach appears attractive due to the elimination of printing, postage, and data entry costs, but was negatively received by patients and NHS providers alike.
  - Postal methodologies proved superior to hand-out (in terms of response rates) in secondary care and pulmonary rehabilitation settings. Similar response rates were achieved from these two methods in primary care but from an administrative point of view a postal approach is favourable as it would reduce burden at practice level. Where practices needed to be directly involved in the survey administration proved to be a significant barrier to participation.
  - A prospective hand-out approach posed challenges in identifying eligible patients at the point of care, making appropriate exclusions, and determining an appropriate length of fieldwork. A postal survey would be easier to standardise in the event of a wider rollout.
  - Although devolution of some aspects of survey implementation was not as great a barrier in secondary care and pulmonary rehabilitation, the cost to the service of a devolved approach (in terms of local staff time and resource) would likely exceed the cost of centralised administration. Centralised administration would also enable assurance about consistency of methods and particularly about patient inclusion/exclusion from samples.

- **Pilot Study Recommendations**

  Based on the pilot results, a number of initial recommendations were made:

  1. In the absence of a validated COPD specific PREM, use of an existing generic tool, with the addition of disease-specific questions on issues of particular importance to COPD patients, provided a basis for measuring people's experiences of COPD care in a range of settings
  2. A national survey in primary care will only be feasible if supported by section 251 approval to enable central administration of questionnaires and reduce burden at practice level.
  3. An online survey approach should not be pursued for a survey of people's experiences of COPD at this time, given a) evidence of extremely low response rates and b) the lack of support for such an approach from patients and providers alike.
  4. A postal survey methodology is recommended for use in the national audit. It elicited reasonable response rates and is easier to standardise in the event of a wider rollout
  5. A fully centralised approach would require section 251 approvals in all settings to allow for patient identifiable data to be shared for the purposes of administration.

  Conclusion: A centralised postal survey, with section 251 support, for each setting would be the approach most likely to be successful for national use.

Implementation Proposal

Having identified a recommended data collection methodology through the feasibility pilot study, further practicalities would require detailed consideration if the recommended PREM methodology is to be successfully integrated into each workstream of the national COPD audit programme in the future. These include:

- Governance
- Staffing
- Delivery - External Provider vs 'In-house'
- PREM Tool/Questionnaire

- Technology
- Data flows and linkage
- Ethical / Information Governance Requirements
- Timing –audits and questionnaires
- Communications, including recruitment strategy
- Data Analysis and Reporting
- Risk Management

An estimation of costs for PREM data collection via centrally administered postal questionnaires for all three settings, based on current costs, totals £[redacted] (ex VAT) per annum. This costing is based on the assumption that pulmonary rehabilitation and secondary care PREM surveys would take place in alternate years; primary care surveys annually. It is anticipated that a year-on-year increase of approx. [redacted]% will need to be factored in for subsequent years to cover inflation costs. These costs will need to be reviewed should there be a significant delay in a decision being made regarding the integration of PREMs into the audit programme.

An implementation proposal has been outlined; a significant portion of work being 'front-loaded' at the start of the project in year 1, e.g. staff recruitment, contracting, ethical / IG approvals.

It is proposed that the central administration of the PREM survey would be undertaken by an accredited external provider. The PREM surveys in each setting would be timed to tie in with organisational and clinical audits in each setting. Utilising the same cohort of patients for the PREM as in the clinical audits would support the linkage of patient-level data for further analysis.

Due to the current review of PROMs and PREMs commissioning at NHS England, it is anticipated that a decision regarding this PREM proposal will not be made in time to enable integration of PREMs within the scheduled pulmonary rehabilitation audit in 2015. It is therefore anticipated that secondary care would likely be the first setting in which PREM data could be collected and linked (as part of the secondary care COPD clinical audit (round 2) in early 2016.

Data flows for the national COPD audit programme are already complex and it is proposed that the national COPD audit programme team would continue to work closely with the Health Research Authority regarding section 251 approvals for the integration of PREMs into the various programme workstreams.

Conclusions and recommendations

Using a postal survey PREM in three different clinical contexts patient responses were over 50%. The evidence from this pilot supports the use of this methodology to collect patient experience of COPD care across primary care, acute hospital care and after pulmonary rehabilitation.

Understanding the views and experiences of patients sits at the heart of current NHS policy. The use of PREMs provides an invaluable opportunity to gain this knowledge and use it to drive improvements in patient care and services.

The national COPD audit programme, with its established strategic partnership working approach, is well placed to pioneer the large scale collection and use of patient reported experience data for a long term condition. The proposed methodology for the integration of PREMs into the audit programme would support the delivery of Government priorities placing the patient at the heart of NHS services; in conjunction with the other COPD audits within the programme providing a rounded view of the quality of COPD care and services across England and Wales and further supporting the transparency, monitoring and improvement of patient services.

Section 1 Introduction

Patient Reported Experience Measures (PREMs) are a key feature on the Government healthcare agenda. PREMs can provide important evidence regarding clinical care from the patient perspective. In conjunction with organisational and clinical audit data, they provide a rounded view of a patient's care experience and support the development of quality improvements.

Chronic Obstructive Pulmonary Disease (COPD) is a common and usually progressive disease and is a leading cause of mortality and morbidity globally: the World Health Organisation estimates that COPD is responsible for 5% of annual deaths globally (World Health Organisation). It causes progressive breathlessness with cough and wheeze, punctuated by exacerbations (flare-ups) that may lead to hospital admission. Whilst 835,000 people in England have been diagnosed with the disease, a further 2 million people with COPD may be unidentified (Department of Health, 2010). COPD is the 5th biggest killer in the UK and the only major cause of death on the increase. Sequential UK national COPD audits (Royal College of Physicians, 2001, 2003, 2008) and other publications, such as the BTS Burden of Lung Disease Report (British Thoracic Society, 2006) and Invisible Lives (British Lung Foundation, 2007) highlight the importance of COPD to the NHS and society. COPD is the second most common reason for emergency admission to hospital. It is estimated that there are 1.4 million annual consultations in primary care for COPD which is four times more than for angina.

1.1 Purpose / Objectives

As part of the national COPD audit programme, one year of development work for the future incorporation of PREMs into the audit programme was commissioned by the Healthcare Quality Improvement Partnership (HQIP); to inform decisions regarding future roll-out of this element and associated funding. (A copy of the PREM workstream deliverables is included as Appendix 2).

The audit programme currently comprises a number of workstreams which are working together to deliver a cohesive work programme, designed to drive service improvement and healthcare quality for COPD patients in England and Wales. The linkage of patient data across COPD audit workstreams and with other data sources (e.g. HES/ONS), using a unique identifier (NHS number), is an innovative and ambitious feature of the audit programme. It provides an opportunity to audit care across the patient pathway and to understand the interactions between quality of care in primary, community and secondary care setting.

The collection of PREMs relating to COPD patients would provide an exciting opportunity to additionally assess care from a patient's viewpoint and to subsequently drive improvement in COPD services across England and Wales.

The main objectives of integrating PREM activities into the national COPD audit programme in the future would be:

- To measure the COPD patients perspective of the care they receive in a number of healthcare settings – primary care, secondary care and pulmonary rehabilitation
- To enable service users to feedback on services and to influence/contribute to service improvement
- To link data at a patient level to provide a complete picture of patient care and experience
- To compare and triangulate patient responses with those gathered through snapshot clinical, and organisation audits, and identify areas of incongruence / similarity
- To provide clinicians with patient feedback to compare against and complement their local clinical audit results and inform quality improvement activities

- To enable provider comparisons and national benchmarking by publically reporting findings; monitoring changes over time, and enabling commissioners to assess the quality of contracted services
- To support the reduction of inequalities across COPD services
- To support openness, transparency and candour throughout the healthcare system about matters of concern (Francis Report)
- To contribute to the body of evidence about PREMs – in terms of both methodology and the use of PREM data to drive improvements in patient care

1.2 Methodology

This document details development work undertaken to assess the feasibility and practicalities of incorporating PREMs into each workstream of the national COPD audit programme.

A number of condition specific potential challenges were identified early in the project, including:

- The demographics of COPD patients (older, with potential communication and cognitive impairments) with implications for the acceptability and accessibility of data collection models, and
- The varied settings in which the COPD PREM feasibility study was to be piloted

It includes the full report of a feasibility pilot study undertaken by the Picker Institute Europe on behalf of the programme (appendix 4), which incorporates a literature review of existing PREM tools and work undertaken piloting the appropriateness of various data collection methodologies in three settings - primary care, secondary care and pulmonary rehabilitation. Recommendations from this report are used to inform a proposal for the integration of PREMs into each audit workstream in future audit rounds.

Delivery of the pilot feasibility study has been managed by the British Lung Foundation, on behalf of the national COPD audit programme, working with the Picker Institute Europe. The work has been guided by a PREM workstream advisory group, chaired by Professor Mike Roberts, with group members incorporating a wealth experience gained in varied healthcare settings.

Section 2 Patient Perspectives: Background / Current Landscape

This section provides an overview of work to date regarding patient perspectives on the health sector, including patient satisfaction activities, PROMs and PREMs. Some examples of other national audit activity in relation to patient experience are also included.

There is high level agreement that patient-centred care sits at the heart of healthcare services. Listening to, and acting on, patients' views are essential to providing such a patient-centred health service and the measurement of patients' perspective of health services and care has become a core part of health policy in the UK.

The NHS Constitution (Department of Health, 2013) highlights the importance of involving patients, carers and the public in shaping and improving services; encouraging and welcoming feedback on health and care experiences for use in improving care and services.

National health policy in England identifies patient experience as an equal component of health services quality alongside clinical effectiveness and safety (e.g. Darzi, 2008a, 2008b), with priorities focussing on 'Putting Patients First' (NHS England, 2013). The challenge to the system has been how best to measure patients' experience of health services and care.

The need for an increased emphasis on patient experience and engagement is further placed high on the agenda by recent publications such as 'Transforming care: A national response to Winterbourne View Hospital' (Department of Health, 2012) and the Francis Report (Department of Health, 2013).

'Everyone counts: Planning for Patients 2013/14' (NHS Commissioning Board, 2012), highlights the importance of patient participation; that health services should be shaped by what matters most to patients and the public.

2.1 Patient Satisfaction

- **Surveys**

- **2.1.1 National**

  The NHS patient survey programme systematically gathers the views of patients on the care they have recently received using a range of health care services provided by the NHS. The programme enables healthcare regulators, eg the Care Quality Commission (CQC), and others to build up a national picture of people's experience, providing comparisons of:

  - performance of different organisations
  - changes over time
  - variations between different patient groups.

  Since 2002 over 1.6 million patients have been reported on their recent experiences of NHS care (Picker Institute). Questions are discussed and tested extensively with patients before being included in each survey, and are developed in response to what patients say is important to them about their care and treatment.

  Patients are asked specific factual questions about what happened to them during their recent healthcare experience. Once results are received, each healthcare organisation is encouraged to share and make use of the findings in order to improve their services locally. The results are also used in a range of ways, including the assessment of NHS performance as well as in regulatory activities such as registration, monitoring ongoing compliance and reviews.

  Surveys to date have included:

- Ambulance survey of 'Hear and Treat' callers 2013/14 – which experiences of over 2,900 people who called an ambulance service in December 2013 and January 2014
- Inpatient survey 2013 - experiences of over 62,000 people who were admitted to hospital with at least one overnight stay
- Maternity services survey 2013 - experiences of over 23,000 women who had a live birth between January - March 2013
- Community mental health survey 2013 - collected information from over 13,000 people who received community mental health services in 2012
- Accident and emergency 2012 - collected the experiences of almost 46,000 patients who had received care from an accident and emergency department at the beginning of 2012
- Outpatient survey 2011 - patients' experiences of their most recent visit to an outpatient department

Current surveys include:

- 2014 NHS National Children's Inpatient and Day Case Survey
- Accident & Emergency Department Survey 2014
- Adult Inpatient Survey 2014
- Ambulance Trust surveys
- Community Mental Health Survey 2014

Five organisations have been approved by the Care Quality Commission to carry out surveys for the patient survey programme. NHS providers (eg Trusts) are required to fund delivery of the surveys locally but may commission one of the approved contractors without further tendering the work. Approved contractors are as follows:

- Capita Surveys and Research
- Patient Perspective
- Picker Institute Europe
- TNS-BMRB
- Quality Health

Their role includes developing questionnaires and accompanying documentation; advising on how to conduct surveys and collating, checking and analysing survey data

2.1.2 Local

In addition to the requirement for them to take part in national surveys, NHS organisations also frequently undertake their own local patient surveys. An online survey of Trusts in England - The National Survey of Patient Experience Practice in the NHS - was commissioned in 2012 by the NHS Institute for Innovation and Improvement (Ipsos MORI, 2012). It looked at current practices among Trusts collecting and using patient experience data and showed a broad variation in methods employed to collect patient data at a local level.

There are a range of tools and guides available to support NHS organisations to carry out local patient surveys, e.g. in using the same questions and approach as are employed in the NHS patient survey programme (NHS Surveys 2014). In doing so, this helps organisations to ensure that their results are comparable with previous surveys undertaken as part of the nationally coordinated programme.

The potential for survey duplication is a potential issue and local organisations are encouraged to take appropriate actions to avoid duplication, eg checking that the same or similar survey is not already planned as part of CQC national patient survey programme and, if it is, avoiding overlapping fieldwork periods and/or by cross checking samples to avoid surveying the same patients twice.

2.2 PROMs

Patient Reported Outcome Measures (PROMs) measure quality from the patient perspective. Typically, short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time. The information collected from patients via PROMs questionnaires before and after an intervention provides an indication of the outcomes or quality of care delivered to patients.

An interim report by Lord Darzi on the future of the NHS (2007) recommended that PROMs should have a greater role in the NHS and his subsequent report 'High Quality Care for All' (2008) identifies PROMS as a means of assessing effectiveness of care from the patient perspective (Darzi 2007; 2008).

The collection and reporting of PROMs was set out as a key priority in the White Paper*, Equity and Excellence: Liberating the NHS* (Department of Health, 2010) where the commitment was made to 'extend PROMs across the NHS wherever practicable". It also promotes widespread use of patient experience data including surveys and real-time feedback to enable patients to rate both services and clinical departments according to the quality of care received.

In addition to supporting patient and clinicians on making better decisions, PROMs can also enable comparisons of providers' performances to stimulate service improvements and their routine use has the potential to transform healthcare (Black, 2013).

The national PROMs programme is NHS England led and uses a number of accredited suppliers to support delivery of the programme. Each participating provider is responsible for the collection of their own PROMs data and it is their choice as to which of the approved suppliers they use.

It is a mandatory national programme, initially covering four elective clinical procedures - hip replacements, knee replacements, groin hernia and varicose veins - a Standard NHS Contract for Acute Services requirement for all NHS-funded providers of these elective procedures. The programme does not cover emergency cases. From 1 April 2009, all providers of NHS-funded care in England have been required to collect PROMs for these four clinical areas. The PROMs programme is limited to England however; a small number of patients from Scotland and Wales will be included in the national analysis due to being treated at English providers.

PROMs calculate the health gain after surgical treatment through the completion of pre and post-operative surveys. Eg A hip replacement questionnaire compares a patient's own assessment of their mobility and pain before and after a hip operation, thus creating a measure of clinical success. The pre-operative survey is administered by staff in hospitals; and the post-operative survey, sent to patients 3 months or 6 months after their operation, direct to their home address.

The first linked set of pre-operative and post-operative data was published in 2010 and the results of the PROMs programme are published each month on a rolling basis by the NHS Information Centre.

Each of the approved suppliers have been contracted to support providers in meeting their PROMs obligations as part of a Framework Agreement (the "Patient Questionnaire Framework") initiated by the DH. Each has been assessed against rigorous quality requirements including Information Governance requirements to ensure that they offer a high quality service.

A number of organisations in the UK and worldwide, including approved suppliers, are working on developing PROMs, eg Quality Health are currently working on a trauma PROM, a PROM for stroke patients, for Mental Health patients, for Melanoma patients in Australia and for a worldwide PROMs programme for Bupa.

2.3 PREMs

Patient reported experience measures (PREMs) can provide valuable information from the patients' perspective on their care. Specifically, we define 'patient experience' or 'PREMs' as distinct from 'satisfaction' or 'outcomes'. They focus on experience of the process rather than the outcome of care. Rather than giving subjective ratings of satisfaction, PREMs focus on asking people to report whether specific events occurred during their care; this approach provides more readily interpretable and actionable data (eg Cleary 1998, 1999). Similarly, PREMs focus on people's lived experiences of care and treatment, rather than the effectiveness of interventions.

In *'Liberating the NHS'* (Department of Health, 2010), it is recommended that there should be more widespread use of patient experience surveys, with patients rating services and clinical departments according to the quality of care they have received. It is intended that this feedback will encourage providers to be more responsive and support the improvement of care and services.

Some argue that patient experience measures bear little relation to the quality of care delivered, however other studies have found that better patient experiences are associated with better outcomes (Manary et al, 2013); that overall satisfaction with care is positively correlated with clinical adherence to treatment guidelines (Jha et al, 2008); and that there is evidence of a relationship between patient experience, effectiveness, and safety (Doyle, Lennox, & Bell, 2013).

Typically, patient experience surveys seek to measure the issues of greatest importance to the majority of patients (Graham & Woods, 2013). In considering a condition specific PREM, decisions about content should therefore be driven – at least in part – by evidence from patients on what matters to them. In relation to COPD, a number of studies have used qualitative methods to explore this. Eg an exploratory study with six COPD patients, found that patients particularly valued being enabled to participate in physical and social activities (Williams et al 2007). Similarly COPD patients were found to be frequently frustrated by the impact that their symptoms, particularly breathlessness, had on their family and social activities (Barnett, 2005)

It is therefore desirable for the assessment of the quality of services to include measures of both clinical performance and the experiences of users where possible; and for the experiences measured to be focused on what matters to patients with that specific condition.

To date, approaches to measuring PROMs and PREMs have been developed separately but there is a view that there should be more close alignment between the two (Manary et al 2013). Eg the Outcomes and Experience Questionnaire (OEQ) was commissioned by the Department of Health with a view to integrating patients' perceptions into a short single measure. The advantages of short and simple tools like OEQ are that they are easy complete by patients and similarly easy to process, whilst bringing together patient perceptions in terms of outcomes of services and experiences of care.

2.4 Other Activities

In addition to the measurement of patient perceptions on health care, converting reported outcomes and experience into improved care and services for patients is the crucial next step.

Established on 1 April 2013, and hosted by NHS England, NHS Improving Quality (NHS IQ) is the 'driving force for improvement across the NHS in England' (NHSIQ, 2014), working to improve health outcomes for people by providing improvement and change expertise. Within NHSIQ, the Patient Experience team focuses on ensuring that those involved in the patient pathway enjoy a positive experience of care; using the information provided by service users to help change patient care delivery.

Eg The Cancer Patient Experience Survey (CPES) collects data on the experiences of cancer patients as part of the national survey programme commissioned by NHS England. NHSIQ is

working with NHS England to support a programme of work exploring how the NHS is using CPES data to reduce variation in the cancer patient experience and support improvements across the process of care. The Cancer Patient Experience Advisory Group (CPEAG) provide oversight to the work programme and the first phase of work, in partnership with Macmillan Cancer Support, is exploring how providers interpret and act upon CPES data to help them improve the patient experience.

2.5 Experience from other national audits

A number of other national audits have explored various aspects of collecting PREM data.

- National Diabetes Audit (Health and Social Care Information Centre, 2013) – A PREM questionnaire hand-out methodology was tested alongside the main audit between November 2013 and January 2014, with an online survey made available to patients attending any one of sixty registered diabetes services in England and Wales (including 28 hospital trusts, 13 GP practice, and one specialist service). The overall number of responses received was low: n=714, an average of n=11.9 per site or n<5 per site per month (the size of the services involved is not reported so it is not possible to calculate a response rate). There was substantial variation between sites in terms of the number of responses received. Patients who responded were typically less likely to be from the oldest age groups, to have type two diabetes, and to be from a deprived background. More than half of all respondents for whom a postcode was available were from the two least deprived quintiles based on their Index of Multiple Deprivation Score, compared with around a third in the audit proper.

- UK Inflammatory Bowel Disease Project (Clinical Effectiveness and Evaluation Unit, RCP) – this audit collected patient reported data for a cohort of patients in 2010/11. Patients were able to submit responses online or via a paper questionnaire. 30% of the audit cohort responded. Of which, approximately 5% of respondents completed the online version. A number of issues were highlighted including:
  - An unprecedented amount of qualitative data were received which the project did not have sufficient resources to analyse
  - The volume of hardcopy forms was unexpected, considering the median age of patients was mid-30s, a cohort expected to be technologically astute

- Sentinel Stroke National Audit Programme (SSNAP) (Royal College of Physicians, 2013) – a desk research based options appraisal of various methodologies for routinely collecting patient reported data was undertaken in 2013, and the feasibility of expanding the scope of the national stroke audit to include patient reported data on a large scale. The study concluded that the preferred option for integration of PREMs/PROMs into the sentinel stroke audit programme is via a proposed RCP 'in-house' PREMS/PROMs hub, rather than outsourcing to a third party. This option enabling full ownership and flexibility of the process of data collection and developing 'in-house' skills which could be applied to other projects.

- Picker Institute (in collaboration with RCP Stroke Programme) - In 2004 and 2005, the RCP Stroke Programme collaborated with the Picker Institute to carry out two national surveys of patients' experiences of stroke care on behalf of the Healthcare Commission. These data were triangulated against those submitted by hospitals over a 3 month period as part of the retrospective snapshot National Sentinel Stroke Audit (Round 4). The first survey (40 questions) asked patients about the care and treatment they received in hospital; the second (40 questions) asked about their longer term care. Questionnaires were sent to patients by trusts (funded by the Department of Health). Stroke patients were involved in designing the questionnaire and the Different Strokes, Speakability and the Stroke

Association were consulted during the development of the surveys. One in three (51) hospital NHS Trusts in England took part in the surveys. In autumn 2004, 1713/2786 (61%) patients responded to the first survey. Over 70% of these respondents agreed to take part in the second survey.

An academic study published following the collaboration concluded that future evaluations of stroke services should undertake both an audit of clinical records and a patient survey for a complete assessment of care (Howell et al 2007).

- National COPD Audit: Patient Survey (Clinical Effectiveness and Evaluation Unit, RCP, 2008) – run in conjunction with the national clinical audit 2008. 30 patients admitted with a COPD exacerbation per participating organisation were given a questionnaire for completion and return to the RCP in a pre-paid envelope.
  - The response rate was 45% (2861/6354)
  - 60% of patients were aged 70+; 21% aged 80+

- Royal College of Paediatric and Child Health – the PREM for urgent and emergency care measures the experience of paediatric patients 0-16 years in all urgent and emergency care (U&EC) settings including GP surgeries, walk-in centres, emergency departments and the ambulance service. The tool was developed by the RCPCH, with Picker Institute Europe, and developed 'by the children, for the children'. Previously, many paediatric patient surveys had been developed by adults with little or no input from children and young people. Information on findings is not publicly available.

Section 3 Feasibility Study

This section provides an overview of the findings of the commissioned feasibility study, undertaken by the Picker Institute Europe. A full copy of the report is included as Appendix 4.

3.1 Introduction

The Picker Institute report looks at the feasibility of integrating PREMs into the national COPD audit programme. It considers a range of approaches to measuring people's experiences of COPD in three key settings: primary care, secondary care, and pulmonary rehabilitation (PR). Within each setting, the pilot sought to assess the feasibility of a number of independent approaches to see if any would offer an acceptable balance of cost, representativeness, and data quality.

3.2 Pilot Study - Methodology

3.2.1 PREM Tool (Questionnaire)

The project focussed on testing methods and assessing the feasibility of collecting PREMs as part of the national COPD audit programme. In the absence of any existing validated COPD specific PREM tools, the project aimed to use a generic tool, or tools, for piloting.

A literature review identified a number of potential generic questionnaires. These were tested with patients via focus groups to ensure their broad suitability and to assess the extent to which tailoring across and within settings would be necessary.

Four focus groups were undertaken with people with COPD, via British Lung Foundation Breathe easy Groups, to get their views on the aspects of care that mattered to them, to test out the generic questionnaires, and to seek their views on preferred means of being contacted in a survey. 30 people took part in the focus groups (17 male, 13 female) - eligibility criteria for the focus groups is detailed in appendix 4.

In terms of survey administration, the following preferences were expressed:

- Unanimous preference for a paper self-completed questionnaire
  - Ideally sent to home or given to complete within each setting
  - If completed in-situ, the person administering should not be involved in their care and an alternative option to send back by post should be given
- An online survey was considered inappropriate. If considered as an option, assistance to complete within a healthcare setting could be required (ideally via volunteers rather than healthcare staff)

The following questionnaires were identified as appropriate for use, with the addition of some COPD specific questionnaires covering issues per setting, as identified by the focus groups.

- Primary Care: GP Patient Survey (GPPS)
- Secondary Care: Picker Patient Experience Questionnaire (PPE-15)
- Pulmonary Rehabilitation: Rehabilitation Questionnaire

3.2.2 Data Collection

The PREM pilot employed three methodologies:

- Method one – paper survey, sent via post
- Method two – paper survey, handed out at the point of care

- Method three – online survey, distributed via postcard at the point of care.

Each methodology was tested in the three settings – primary care, secondary care and pulmonary rehabilitation (a three-by-three nested design).

The pilot was designed to assess the feasibility of a devolved survey in which questionnaires were administered by the pilot sites themselves so that no patient identifiable data would need to be shared with the Picker Institute and thus avoiding the requirement to obtain section 251 approval. (Obtaining section 251 approval can be a lengthy process, especially within the context of a complex programme of work. This pilot project was time-limited and attempting to gain approval once tools and methodologies had been confirmed would have extended timelines considerably).

The characteristics of each method were assessed against three criteria: their practical feasibility, the level of data provided, and the likely costs and cost efficiencies for a national rollout. Collectively these factors provide a rounded overview of the feasibility of adding PREMs into the national COPD audit programme.

3.2.3 Recruitment/Participation

Potential pilot sites in the three different settings – primary care, secondary care and pulmonary rehabilitation - were identified by members of the PREM workstream group, and other clinical networks/routes, and invited to take part in the pilot. Despite good initial interest from potential sites, recruiting organisations and ensuring participation proved challenging for a variety of reasons. Eg staff at potential sites reported they had limited capacity to support a pilot study; others felt that involvement would require additional financial support to cover their costs.

3.2.4 Sample Size

Sample sizes were tailored to each pilot site, taking into account their patient numbers and overall target sample sizes for each setting.

3.3 Findings

There was a consistent pattern of responses across all three settings. Postal survey responses were highest (51.1% overall), followed by paper hand-out (25%) and online (4.7%).

Developing and rolling out the pilot highlighted a range of challenges and barriers associated with using a PREM tool in support of a COPD audit. Proposed data collection tool(s) and methodology will need to address these if the benefits of collecting COPD PREMs are to be realised.

3.3.1 Challenges / Constraints / Assumptions

- **Setting specific**
  - **Primary Care**
    - Piloting in primary care was considerably more difficult than in other settings, which appeared to be largely due to the input required from practices.
    - Distributing questionnaires was perceived to place too great a burden on staff.
    - Remuneration was requested by potential pilot sites to cover staff time involved in administration however practices were subsequently unable to provide an estimation of what these costs might be.
    - Administration of the questionnaire, including the identification of eligible patients, by staff members other than the medical team treating the patients was problematic given their limited access to clinical information.
    - Timing of the survey was highlighted as important – with a need to avoid peak times (such as QOF)

- Recruitment of a total of only three pilot sites in primary care took very extensive efforts over a protracted period of time. This level of input would not be sustainable across a national study.
- Realistically, if a survey were to be implemented nationally, this would almost certainly need to be centrally administered and necessitate section 251 approval for patients' names and addresses to be directly accessed by the survey provider without prior informed consent. The challenge of obtaining this should not be underestimated.

- **Secondary Care**
- There was concern that the response rate would be low as, depending on timing, patients would be too ill to take part. (The pilot response rate for acute trusts was lower than pulmonary rehabilitation across all methodologies).

- **Methodology**
  - **Method 1 – Paper (Postal distribution)**
  - Difficulties in identifying patients who lacked cognitive capacity, or were too ill, to complete a questionnaire.
  - Also in the identification of deceased patients, without further checks/processes.
    - These issues were mitigated in the pilot by inclusion of a Freephone number to call to prevent reminders being sent if patient unable to complete to questionnaire; a common practice in national surveys.
  - Prohibitive cost and burden at site level in drawing the sample and administering the survey.

  - **Method 2 – Paper (Hand-out)**
  - Implementing method 2 in any of the settings faces barriers relating to the consistent administration of questionnaires and application of inclusion and exclusion criteria. In response to a staff request, a draft 'script' was produced for pulmonary rehabilitation, at a later stage in the pilot process, to use when handing out questionnaires.
  - Feedback from pilot sites indicated that they preferred to exclude patients with impairments that they felt would preclude their participation in the survey so as not to unduly burden or distress them. There was therefore tension between utilising the expertise of clinical staff in identifying and assessing the appropriateness of patients versus the desire to limit burden. Eg in primary care the only person not directly involved in care is often the receptionist, who does not then have access/knowledge to identify/exclude appropriate patients.
    In some cases, a pragmatic approach was taken, allowing clinicians to be directly involved in the administration of questionnaires or invitations. This is not ideal, both in terms of the risk of it biasing responses because it may seem coercive to patients and also because of the danger that it be seen to draw time away from front line care. For the pilot, there was not always a realistic alternative, which draws into question the feasibility of a hand-out approach for any national collection.
  - Prohibitive cost and burden in locally drawing the sample and handing out the survey.
  - Response rates for method 2 were considered reasonable - stronger at 48.3% in primary care but relatively low in secondary care (27.4%) and pulmonary rehabilitation (31.7%).
    Responses rates varied between sites implementing this method which suggests there may have been differences in the way the survey was administered. E.g. response rates in PR with method 2 ranged from 0% to 80%. The pilot study did not explore the factors behind response rate variation, or how it might be minimized.
  - Some participating organisations insisted on personalisation of pilot materials, e.g. inclusion of their own logos.
  - In considering costs, overall response rates for method 2 could provide cost effective data <u>but</u> these costs do not factor in the greater investment required in terms of front-line staff time.

- **Method 3 – Online (Login details provided at point of care)**
  - This method was unpopular both with patients in focus groups and with pilot sites, on the grounds that a large proportion of COPD patients are likely to have difficulties accessing and using computers and the internet.
  - A sizable proportion of patients offered a postcard to complete the survey online refused it because they did not have internet access. In one acute trust, a total of 11 postcards were handed out, with a further 21 postcards refused by patients due to no internet access. (Subsequently none of the 11 patients completed the online survey).
  - As expected, response rates were also exceedingly low: only four responses were received, all from PR patients, and the overall response rate was less than 5%. This reduces the potential for an online survey to provide cost efficiencies and unless a much higher response rate could be achieved – an online survey is unlikely to be cost-effective.
  - Taking together, the objections of patients, the likely exclusion of many, the very low response rates and risk of non-response bias, an online survey approach using the piloted methodology is not recommended.

- **Site Recruitment/Participation**
  - The pilot study had a number of limitations; the most significant of these being the self-selecting nature of participating sites. Pilot volunteer sites may differ from other trusts and practices in England and Wales, both in terms of their patient populations and in terms of their own levels of engagement. This may have had an effect on response rates and results. It is reasonable to consider that volunteer pilot sites may be more motivated than others to allocate resources to implementing a survey, or may have more resources available to do so. Their participation may also be motivated by a predisposition to take the measurement of patient experiences seriously.
  - As previously mentioned, the direct involvement of organisations in the administration of surveys proved challenging, with organisations indicating a lack of resources and, in primary care, a need for additional financial support in order to participate.
  - The recruitment process was easier in some settings than others. In pulmonary rehabilitation, the primary organisation contact identified was generally able to commit the service to participate, take responsibility for overseeing the administration of the survey and respond to communications. However, in secondary care the process was often more complicated, often with one consultant required to commit to participate and liaison with another clinician required re administration.
  - Common recruitment questions related to ethical approval and likely time/workload implications.
  - The resources that went into recruiting sites to the pilot study, particularly in primary care, are not replicable on a national scale. In that respect the findings do not reflect the feasibility of implementing a national survey along the lines of the pilot methods. However, the pilot does highlight the process modifications that would be required to translate the pilot approaches into a national survey – and where these changes are not feasible.
  - We might reasonably expect the challenges faced in recruiting and supporting sites in implementing the pilot survey to be magnified if these methods were rolled out nationally.

- **Sample Size/Design**
  - The pilot highlighted some practical design issues that would need to be taken into account in planning a wider roll-out. Eg implementing a survey in pulmonary rehabilitation using a prospective sample (method 2) would require a long period of fieldwork to obtain a sufficiently high sample from those sites with relatively small numbers of patients attending their programmes.

- **Patient Selection**
  - Inclusion criteria were based on ICD-10 codes. Questions were raised as to the reliability of the J44 chapter set of codes for identifying COPD patients and whether these codes are consistently/accurately applied.
  - Common across most survey methods, participating organisations were keen to exclude to patients with cognitive impairments or those who were considered too unwell so as not to unduly confuse or burden patients. Identifying this patient group posed challenges (particularly with method 1).

- **PREM Tool**
  - Both focus groups and desk research highlighted that a fairly consistent approach to *what* should be measured in different settings could be productive: there was good consistency in the issues that mattered to patients in primary care, secondary care, and pulmonary rehabilitation.

- **General**
  - **Costs**
    - In primary care, a study producing representative data for every GP practice would be cost prohibitive. Sampling at CCG/LHB level is deemed more achievable.
    - In secondary care and pulmonary rehabilitation, a starting sample could be linked to the main COPD audit cohort.
    - Pulmonary rehabilitation is challenging to cost in that the estimated sample size is difficult to estimate as numbers using services are not currently reliably known.
    - Economies of scale are available for larger sample sizes; therefore a Trust/CCG/LHB level sample is more cost effective per response cost than a national level survey.
    - Estimated fixed costs could potentially be reduced if the administrative process of selecting patients, negotiating access to patient data items and obtaining necessary approvals (eg s251) approval could be streamlined.
    - The costs of a survey will be largely influenced by sample size.

  - **Pilot Survey Results**
    - The purpose of the pilot was largely to test the feasibility and practicalities of collecting data, rather than to provide a thorough understanding of the experiences of people with COPD in the different settings, with 'off-the-shelf' questionnaires rather than bespoke instruments utilised. The use of substantive results from the pilot is limited by the fact that pilot sites are not expected to be wholly representative. However the results do give an indication of what might be expected from a national survey, particularly for secondary care and PR where more responses were received and a wider set of sites involved. Specifically, results for all PR sites were exceptionally positive.

3.4 Summary of Key Lessons Learned

Designing and implementing the pilot provided valuable evidence about the feasibility and practicalities of including PREMs in the national COPD audit across the three settings.

- The domains of care that matter to healthcare patients in generic terms are well understood and reasonably consistent, but relatively little work has looked specifically at the requirements of people with COPD or at how people's COPD specific experiences should be measured. Findings from the focus groups gave a good sense of these more specific issues.
- In planning and conducting the pilot survey, many key findings and learning points related to the practicalities of getting the survey to the patient; these are not trivial when considering the potential integration of PREMs to a national audit programme.
- The use of an online survey approach appears attractive due to the elimination of printing, postage, and data entry costs, but was negatively received by patients and NHS providers alike. Concerns

focussed on the suitability of an online survey for the COPD population. Moreover, few responses were achieved and, given the very low response rate, Picker Institute calculate that an online survey approach would, counter intuitively, offer worse value for money that the more traditional alternatives.

- Postal methodologies proved superior to hand-out (in terms of response rates) in secondary care and pulmonary rehabilitation settings. Similar response rates were achieved from these two methods in primary care – possibly as it was easier for primary care patients to complete the survey whilst still at the practice – but from an administrative point of view a postal approach remains favourable as it reduces burden at practice level.
- The greatest challenges in primary care were where practices needed to be directly involved in the survey administration. This proved to be a significant barrier to participation. Feedback was that asking general practices to take responsibility for survey administration placed too great a burden on them, especially if this coincided with other peaks in demand (eg around QoF returns).
- A prospective hand-out approach raised distinct challenges in terms of identifying eligible patients at the point of care, making appropriate exclusions, and determining an appropriate length of fieldwork (to accommodate variation in the volume of patients treated and response rate per site). It was easier to standardise – and would be easier to standardise in the event of a wider rollout – with a postal survey.
- Similarly, the involvement of local staff in handing out surveys proved challenging in other settings: it was considered inappropriate to ask clinical staff to administer surveys, but other staff did not always have the information they needed to take a consistent approach to selecting and excluding patients. In some cases, there was no practicable alternative to involving clinical staff, which is not ideal for varied reasons.
- Although devolution of some aspects of survey implementation was not as great a barrier in secondary care and pulmonary rehabilitation, the cost to the service of a devolved approach (in terms of staff time and resource) would likely exceed the cost of centralised administration. Centralised administration would also enable assurance about consistency of methods and particularly about patient inclusion/exclusion from samples.

3.3 Study Conclusions and Recommendations

The findings of the pilot showed substantial differences and clear trends between methods. Learning also informed an analysis of the costs of different options, suggesting clear differences in the value for money associated with different options. (Further detail can be found in Appendix 4).

Of the three methods tested, the Picker Institute found a postal survey approach to have the greatest potential to be used as a common standard: this methodology was associated with the highest response rates within each of the three settings and provided reasonable value for money. Hand-out approaches were at risk from variation in selection and exclusion, and an online approach proved unpopular with providers and patients.

Based on the pilot results, a number of initial recommendations have been made:

1. In the absence of a validated COPD specific PREM, use of an existing generic tool, with the addition of disease-specific questions on issues of particular importance to COPD patients, provided a basis for measuring people's experiences of COPD care in a range of settings
2. A national survey in primary care will only be feasible if it is supported by section 251 approval to enable central administration of questionnaires and avoid dependency on busy general practice staff.
3. An online survey approach should not be pursued for a survey of people's experiences of COPD at this time, given a) evidence of extremely low response rates and b) the lack of support for such an approach from patients and providers alike. This should be reviewed in the next 5-10 years as patterns of internet access and use, and technological developments, may change over this period.
4. Postal methodologies proved superior to hand-out (in terms of response rates) in both secondary care and pulmonary rehabilitation settings and a postal survey is also easier to standardise in the

event of a wider rollout Therefore a postal survey methodology is recommended for use in the national audit.

5. A fully centralised approach would require section 251 approvals in all settings to allow for patient identifiable data to be shared for the purposes of administration.

Conclusion: A centralised postal survey, with section 251 support, for each setting would be the approach most likely to be successful for national use.

Section 4 PREM Implementation Proposal

This section:

- Summarises some of the areas for more detailed consideration if the recommended PREM methodology is to be integrated into teach workstream of the national COPD audit programme in the future.
- Provides an early project risk assessment
- Details a current estimated annual costing for the integration of PREMs across the programme, and
- Outlines a suggested implementation proposal

4.1 Future Implementation Considerations

4.1.1 Governance

An appropriate governance structure will need to be implemented, including the establishment of a workstream advisory group and appointment of a workstream clinical lead.

Impact on the work of other workstreams will need to be taken into account and any anticipated additional roles and responsibilities for partner organisations will need to be formally agreed (and contracted).

4.1.2 Staffing

The integration of a PREM workstream into the national COPD audit programme will bring with it an additional workload which will require additional core staffing to support effective delivery.

4.1.3 Delivery - External Provider vs 'In-house'

There are two potential options for the delivery of a centrally administered postal survey – i) delivery by the central COPD audit team based at the Royal College of Physicians or ii) contracting the PREMs administration to an accredited provider.

- In light of the proposed sample sizes and volume of work, the option of delivery at the RCP would require significant resource in terms of staffing, technology, consumables, etc. and is therefore not considered viable at this time. However, this option should be regularly reviewed as any future development of PREMs in other national audit programmes led by the RCP might enable economies of scale for 'in-house' PREM delivery.
- The benefit of external providers is that they have considerable experience and have themselves built up economies of scale, leading to efficiencies and cost effectiveness through use of standardised approaches. They are also generally well equipped to administer large volumes of paper questionnaires, provide a helpline for participant queries and implement a robust follow up strategy, which could help to support higher response rates.

4.1.4 PREM Tool/Questionnaire

The pilot study suggests that existing core domains, such as the NHS Patient Experience Framework, could provide a basis for measuring patient experiences of COPD care in a range of settings, with the addition of some COPD specific questions. There may be benefits to the use of a tool with at least a core of generic items, as these support standardisations across patient groups and subject areas, and thus a greater understanding of patient experiences of healthcare and comparison with wider health communities.

Outside of this commissioned project, the development and validation of a short COPD PREM, led by Matthew Hodson (Homerton University Hospital NHS Foundation Trust) is nearing completion. It is proposed that this could be used, in conjunction with a core generic set of questions, to collect PREM data, if the integration of PREMs into the audit programme is agreed.

Looking to the future, it may be that one annual national online PREM survey, comprising of a generic question section supplemented by sets of dropdown condition specific questions (availability of sub-sets being patient specific) becomes a more efficient and cost-effective method of gathering patient-level experience data for a range of conditions across England and Wales.

4.1.5 Technology

Whilst a paper based methodology is currently recommended by the pilot study, technological developments (and their costs) rapidly change. The use of different modes of questionnaire delivery should be reviewed regularly and the potential for use of new technologies assessed.

4.1.6 Data flows and linkage

Linking PREM data to other COPD audit workstream data, utilising a common study ID (pseudonymised NHS number, in line with other COPD audit workstreams), will be challenging. This is due to the proposed addition of a PREM external provider to the already complex programme structure, and the additional flow of patient identifiable between various organisations required to support the central administration of a PREM survey. If integration is approved, early work would be required to ensure that data flows are the most effective and meet the requirements of the Health Research Authority and other partner organisations such as the Health and Social Care Information Centre at that time.

4.1.7 Ethical / Information Governance Requirements

Information governance requirements are a key consideration in the integration of PREMs to the national COPD audit programme. Section 251 approval would be required to enable the collection (without patient consent) and transfer of the additional patient identifiable data items needed to enable the central administration of a postal survey by an external provider.

In addition to administrative requirements, patient identifiable data items will also be required to support the transfer and linkage of data within the programme, including data linkage across audit workstreams, e.g. to link patient level secondary care COPD PREM data with secondary care COPD clinical audit data for further analysis .

It is not envisaged that separate ethical approval will be required; the work falling into the category of audit / service evaluation which is exempt from the requirement. However, in the pilot, some of the most frequently asked questions asked in primary care related to ethics approval requirement. It might therefore be considered good practice to obtain approval on a voluntary basis (via a single multi-site application) as this may allay practice staff fears and support buy-in at a local level.

4.1.8 Timing –audits and questionnaires

It is intended that the PREM surveys would be dovetailed in terms of timing with the appropriate COPD clinical audit.

The timing of questionnaire distribution for each audit setting will require further discussion and agreement, e.g. the period post discharge from an acute trust that a patient is sent a questionnaire. The central distribution of questionnaires, post discharge, poses issues, as outlined in the feasibility study, regarding the identification of deceased patients, or those with cognitive impairment. Mitigating actions will need to be agreed to reduce the potential impact of these issues.

4.1.9 Recruitment Strategy

To maximise participation, a targeted recruitment strategy will need to be developed and implemented, working closely with our partner organisations, in particular the British Lung

Foundation, and with colleagues across the other programme workstreams. This should include:

- Ways to raise the profile of the survey, e.g. via Breathe Easy Groups, patient organisations, libraries, partner organisations. Also to raise the profile across healthcare organisations.
- A follow-up strategy, to encourage questionnaire submissions from non-respondents.

4.1.10 Data Analysis and Reporting

It is anticipated that basic reporting, at appropriate 'site' level will be undertaken by the appointed external provider. A further analysis for national reporting will be undertaken at the Royal College of Physicians. An innovative element of the work will be the linkage of PREM data to corresponding clinical audit data for analysis and reporting. The level of supplementary reporting of linked data required will need to be considered and will affect the costs of delivering the PREM workstream.

4.2 Risk Management

An early assessment of potential risks is briefly outlined in appendix 3. The most significant risk relates to obtaining the necessary information governance approvals (section 251) to collect and transfer the additional patient identifiable data items required to enable the central administration of the survey by an external provider. The structure of the national COPD audit programme is complex, involving a number of organisations in the data management process. The preference in terms of information governance requirements is to keep the number of organisations who have access to patient identifiable data to a minimum. The addition of a PREM workstream, administered by a further external provider, will further complicate the process and may cause concern at the Health Research Authority. It will be important to continue to work closely with the Health Research Authority so that any potential concerns/issues can be mitigated as early as possible in the planning process. All risks should be regularly assessed and monitored, with mitigating actions identified and implemented as appropriate to minimise risk to the work.

4.3 Estimated Implementation Costs

These costs are for the integration of the option recommended through the feasibility study outlined in Section 2 – centrally administered postal questionnaires for all three settings.

These figures provide a rough annual estimate, based on current costs. It is anticipated that a year-on-year increase of approx. 3.5% will need to be factored in for subsequent years to cover inflation costs.

Costs will need to be further reviewed if there is a significant delay in a decision being made regarding the integration of PREMs into the wider national COPD audit programme.

All figures are excluding VAT.

	Notes	Estimated Annual Costs £ (ex VAT)
Core Costs		
Staff Costs	Including clinical leadership, supervision and contribution to partner staff costs	[redacted]
Meeting Costs/Governance		
Admin Overheads	Finance, HR, IT, Building Rent (inc estimated partner additional overheads)	
PREM costs		
Pulmonary Rehabilitation / Secondary Care - **Alternate years** to tie in with	• Based on estimated Picker costs covering administration of PREM questionnaires plus basic analysis and	[redacted]

	Notes	Estimated Annual Costs £ (ex VAT)
organisational and clinical audits - Postal survey centrally administered by external provider alongside clinical audit	reporting (headline results & benchmarks). • Programme level sample/study – Pulmonary rehabilitation; Trust/HB level sample/study – secondary care • More detailed analysis / reporting / linkage by RCP.	[redacted]
Primary Care - Annual - Postal survey centrally administered by external provider alongside clinical audit	• Based on estimated Picker costs covering administration of PREM questionnaires plus basic analysis and reporting (headline results & benchmarks). • CCG/LHB sample/study (n=36,888 patients) • More detailed analysis / reporting / linkage by RCP.	
Pseudonymisation & Linkage	Estimate only	
Additional Reporting and Analysis of Linked Data at RCP	Includes stats time	
Consumables	Including report printing, postage, etc. Cost dependent on level of additional reporting for linked data	
Quality Improvement	Including patient activity/focus groups/events	
Estimated Total	• **NB - This would cover either a pulmonary rehabilitation or a secondary care survey each year, plus an annual primary care survey** • **Costs would need to increase annually in line with inflation at approximately 3.5% per annum**	

4.4 Implementation Proposal

Implementation of the recommended PREM survey methodology is outlined in the table below. A significant portion of work would be 'front-loaded' at the start of the project in year 1, e.g. staff recruitment, contracting, ethical / IG approvals.

It is proposed that the central administration of the PREM survey would be undertaken by an accredited external provider. The PREM surveys in each setting would be timed to tie in with organisational and clinical audits in each setting. Therefore pulmonary rehabilitation and secondary care PREM survey would take place in alternate years; primary care surveys annually. Utilising the same cohort of patients for the PREM as in the clinical audits would support the linkage of patient-level data for further analysis.

We have been advised that the commissioning of PROMs and PREMs is currently under review within NHS England, including options and opportunities for future coverage and roll-out within the National Clinical Audit Patient and Outcomes Programme (NCAPOP). In terms of timings, a decision regarding this PREM proposal will not now be made in time to enable the integration of PREMs within the scheduled pulmonary rehabilitation audit in 2015. It is therefore anticipated that:

- Secondary care would likely be the first setting in which PREM data could be collected and linked, as part of the secondary care COPD clinical audit (round 2) in early 2016. This would require project

set-up to commence early to mid-2015 at the latest to ensure relevant permissions and data requirements are in place to enable the survey to align with the clinical audit timetables.
- In primary care, PREM data collection would also commence in 2016 as part of the annual primary care COPD clinical audit.
- For pulmonary rehabilitation, the first opportunity for PREM integration would be in 2017 (round 2)

Data flows in the national COPD audit programme are already complex and the addition of a further organisation to the mix in the form of an external provider for PREMs may cause issues / concerns in relation to the flow and linkage of data when obtaining information governance approvals. It may be that our choice of data flows or provider is subsequently limited. (In any event, the external provider would need to have completed the requirements of the NHS IG Toolkit). The national COPD audit programme team already work closely with the Health Research Authority regarding section 251 approvals for the various workstreams within the programme and it would be important to liaise with them from an early stage should the integration of PREMs to the programme be approved.

In the meantime, the following processes are proposed. These would need to be subject to further discussion/agreement at the time of any approval for PREM work - with partner organisations in terms of tying in with current COPD audit data processes, and other relevant bodies in terms of data/information governance requirements.

- Primary Care – as part of annual clinical audit, additional patient identifiable data items (name and address) to be added to primary care data extraction dataset. Following pseudonymisation of data at the Health and Social Care Information Centre (HSCIC), patient names and addresses (along with unique study ID - pseudonymised NHS number) to be transferred to approved survey supplier for administration of survey. Following completion of survey, set of data containing patient level survey responses and study ID (but not patient identifiable items) securely transferred to RCP for further analysis and linkage to other audit datasets via unique study ID.

- Secondary Care/Pulmonary Rehabilitation – following completion of either clinical audit each year, the HSCIC would be contracted to centrally extract patient names and addresses for patients included in the clinical audit, using the NHS numbers collected as part of the clinical audit dataset. The HSCIC hold the various patient identifiable COPD audit datasets on behalf of the wider audit programme as an accredited safe haven). Again, patient names and addresses (along with unique study ID - pseudonymised NHS number) to be transferred to approved survey supplier for administration of survey. Following completion of survey, set of data containing patient level survey responses and study ID (but not patient identifiable items) securely transferred to RCP for further analysis and linkage to other audit datasets via unique study ID.

The proposals above are all subject to necessary Section 251 approvals and data sharing requirements being in place.

A programme wide section 251 approval is currently held, with amendments submitted to the Health Research Authority for any additional workstream activities, as required. It is anticipated that the required PREM approvals would be incorporated into this same application. This work would be led by the Royal College of Physicians, rather than the external provider. This is to ensure consistency across the programme and should also help to reduce external provider set-up costs.

Phase	Description	Month
1) Set-up / Initiation	• Staff recruitment • Produce workstream brief/plan/PID for all three workstreams ○ Define objectives, project specification, roles and responsibilities, budget, risks, constraints	1-6

Phase	Description	Month
	• Agree governance structure and establish workstream advisory group • Agree communication strategy • Agree outline project plans/specifications for each setting – primary care, secondary care and pulmonary rehabilitation • Tender for / appoint external provider • Agree data flows, data sharing requirements • Obtain necessary ethical / IG approvals (e.g. integrate work into existing wider national COPD audit programme s251 application and obtain HRA approval) • Establish necessary sub-contracts (or contract variations) with partner organisation to incorporate any appropriate aspects of PREM project delivery	
2) Design	• Agree PREM survey/tool for use in each setting • Agree final methodology, roles and responsibilities and communication requirements with external provider and partner organisations • Consider potential QI activities • (Annually review/renew IG approvals)	3-6 (Annually In month 1-3)
3) Delivery	• Administration of PREM survey by external provider – to tie in with organisational and clinical audits in each setting. (Pulmonary rehabilitation and secondary care alternate years; primary care annually). • Data cleaning and analysis • Initial report at agreed site level by external provider on behalf of programme • Data transfer to HSCIC for pseudonymisation (and linkage. Linkage could alternatively be undertaken at RCP). Then transfer to RCP • Further analysis and reporting at national level by RCP • Supplementary analysis and reporting of linked data by RCP • Agree QI plan, working in conjunction with partner organisations and other bodies	6-12 Timings dependent on timings of organisational / clinical audits in each setting
4) Review	• Review lessons learnt to inform next round of surveys	12
	• Meet with Commissioner to determine plans and funding for further 2 years funding	24

Section 5 Conclusions

Understanding the views and experiences of patients sits at the heart of current NHS policy. The use of PREMs provides an invaluable opportunity to gain this knowledge and use it to drive improvements in patient care and services.

The commissioned development work outlined in this document has explored in detail the feasibility of a number of methodological approaches to collecting PREMs for COPD patients in the three different settings – primary care, secondary care, and pulmonary rehabilitation. The feasibility study has highlighted a range of challenges, and opportunities for effective implementation. Using a postal survey PREM in three different clinical contexts patient responses were over 50%. The evidence from this pilot supports the use of this methodology to collect patient experience of COPD care across primary care, acute hospital care and after pulmonary rehabilitation.

For the pilot, in the absence of a validated COPD specific PREM, use of an existing generic tool, with the addition of disease-specific questions on issues of particular importance to COPD patients, provided a basis for measuring people's experiences of COPD care in a range of settings. Outside of this project, the development and validation of a short COPD PREM is nearing completion. It is proposed that, if the integration of PREMs into the audit programme is agreed, this COPD specific PREM could be used to collect future COPD PREM data.

Information governance requirements are a key consideration in the integration of PREMs. Section 251 approval would be required to enable the collection and transfer of the additional patient identifiable data items needed to enable the central administration of a postal survey by an external provider. In addition to administrative requirements, patient identifiable data items will also be needed to enable data transfer and linkage across audit workstreams in the audit programme, e.g. to link patient level secondary care PREM data with secondary care clinical audit data for further analysis . Experience gained to date in obtaining approvals for other COPD audit workstreams has shown that the time, and potential issues, in gaining the necessary approvals is not to be underestimated and will need to be further reviewed in light of the data / information governance landscape at the time a decision is made in respect of this PREM proposal.

The structure of the national COPD audit programme is multi-faceted, with a number of organisations involved in the collection, analysis, pseudonymisation and linkage of data. Linking PREM data to other COPD audit workstream data, utilising a common study ID, will also not be without its challenges due to the likely addition of a PREM external provider to the already complex programme structure, and the additional flow of patient identifiable required. However, the challenges are not insurmountable and early work would be required to ensure that data flows are the most effective and meet the requirements of the Health Research Authority and other partner organisations such as the Health and Social Care Information Centre.

The national COPD audit programme, with its established strategic partnership working approach, is well placed to pioneer the large scale collection and use of patient reported experience data for a long term condition. The proposed methodology for the integration of PREMs into the audit programme would support the delivery of Government priorities placing the patient at the heart of NHS services; in conjunction with the other COPD audits within the programme providing a complete view of the quality of COPD care and services across England and Wales and further supporting the transparency, monitoring and improvement of patient services.

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Appendix 1: National COPD Audit Programme – PREM Workstream Group Members

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- Dr Noel Baxter, GP
- Chris Graham, PICKER Institute Europe
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- Professor Paul Jones, St George's University of London
- Mike McKevitt, British Lung Foundation
- Professor Mike Roberts, Royal College of Physicians
- Laura Searle, British Thoracic Society
- Emma Skipper, Royal College of Physicians
- Sally Welham, British Thoracic Society
- Dr Penny Woods, British Lung Foundation

Appendix 2: National COPD Audit Programme – PREM Workstream Deliverables

3	**PREM**
3.1	Convene workstream group to develop and agree project plan
3.2	Explore the availability of current tools and select which ones will be presented to the focus groups
3.3	Three focus group meetings to test the acceptability of tools with patients and explore methods for data collection across the programme
3.4	Design and pilot methods of data collection in acute care, primary care and pulmonary rehabilitation
3.5	Analyse data, evaluate methodologies and opportunities for data linkage
3.6	Submit report with recommendations and costs for integrating a PREM into the National COPD Audit

Appendix 3: National COPD Audit Programme – PREM Risk Assessment

Risk Factor	Probability	Impact	Rating	Mitigation	New Rating
Methodological Risks					
Chosen data collection method is not effective in practice	2	5	10	– Undertake extensive review following year 1 to identify problematic areas and find workable solutions	5
Implementation Risks					
Obtaining ethical / information governance approvals is more difficult than anticipated – unexpected requirements / unexpected delays / approval or specific aspects of approval, refused	3	5	15	– The RCP COPD team works closely with the Health Research Authority regarding the national COPD audit programme s251 approvals and would continue to do so re the integration of PREM related patient identifiable data items, data flows and linkage to determine requirements – Work with partner organisations to ensure that the required data flows and methodologies are most effective and appropriate – Ensure issues of consent, data usage and the 'opt out' process are made clear to patients in various formats	10
Participation Risks					
Low response rate from patients	2	4	8	– Agree follow up strategy with external provider – Ensure communication strategy / plan incorporates ways to raise profile of survey and work with partner organisations to encourage recruitment – Monitor response rates by provider and take appropriate actions	4

For this project, the probabilities of risks occurring were classified as:

- 1 – Low
- 2 – medium
- 3 – high
- 4 – Very High

Potential risk impacts on project were classified as:

- 1 – No impact
- 2 – Little impact: may require extra efforts or activities
- 3 – moderate impact: could cause schedule delays
- 4 – significant impact: could threaten project continuation
- 5 – major impact: could lead to project suspension or termination

Multiplication of probability and impact gives an overall risk rating with:

1 to 6 = Low Risk	8 to 12 = Medium Risk	15 to 20 = High Risk