Key Standards for COPD Care, Management and Treatment
A paper for commissioners of care for people with long term conditions

Executive Summary

Recent research and surveys suggest that there is significant variation in the competence of those delivering COPD care and that the current systems may not remedy this. A joint venture between the two leading clinical British Thoracic Society, and the General Practice Airways Group, IMPRESS, offers some broad standards of competence by which a service for patients with COPD could be judged. The focus is on function and outcome not on which profession does it. However it also stresses the importance of professional standards.

This paper asks eight questions of commissioners and offers standards and markers of good practice for debate and then inclusion in local service specifications.

Questions for commissioners

- Who is accountable locally for ensuring that the workforce has the competence to deliver locally-specified respiratory care? Who takes responsibility for addressing any shortfalls in the short, and longer term?
- Who has the competence locally to judge whether performance is satisfactory?
- What evidence are you using to judge the mix of skills and disciplines you require? Do you have a local clinical multi-disciplinary network to advise you?
- Do you know what was spent last year on training and education in respiratory care? What do you expect to be spent this year? If the budgets are devolved to practices, how do you assure yourselves that the budget is allocated appropriately?
- Who is responsible for looking at the sustainability of the respiratory services?
- What discussions have you held about how to equip the system with the knowledge, skills and attitudes for delivering patient-centred care? How are patients involved in designing and delivering their care? What mechanisms exist for patients' feedback to clinicians?
- What evaluation do you have in place to monitor that changes in skill mix and workforce are leading to positive improvements? Note: IMPRESS will be producing a proposed evaluation framework by the end of April.
- What are you doing to ensure that there is clinical leadership and engagement?

Standards and principles of COPD competences

1. Patients should receive individualised care from knowledgeable practitioners experienced in COPD care.

2. To ensure effective performance, COPD care should be delivered by a range of health care practitioners working as part of a multi-disciplinary team. Any mentally competent patient or member of staff should be able to name who leads the service.

3. Integrated Care: patients should not see the joins, feel pulled in different directions, or be asked unnecessarily repetitive questions – their care should be seamless, continuous, appropriate and responsive no matter who provides the service and no matter how many co-morbidities the patient may have.

4. Patient centred care: patients must be active participants in securing appropriate, effective, safe and responsive care

5. Equity and equality in access

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Purpose

This paper offers commissioners a set of key standards of competence for the delivery of high quality care for people with COPD. It has been produced by IMPRESS[1], a coalition of the societies[2] representing primary and secondary care clinicians with a special interest in respiratory disease, focusing firstly on COPD. IMPRESS campaigns for better integration of care, and offers guidance to clinical colleagues and managers about best practice and thinking. We do not intend to repeat work done by Skills for Health, or anticipate any work on competences developed by the NSF for COPD team. However, we think commissioners might find it helpful to have some broad standards of competence by which a service could be judged. IMPRESS believes this to be important because recent research and surveys suggest that there remains significant variation in care and that the current systems may not remedy this.

Context

Inputs as well as outcomes

Whilst commissioners will increasingly, and rightly, focus on outputs and outcomes, there remains a need for people in the system to understand, consider and challenge *inputs* such as competence, performance and skill mix. As the White Paper Trust, Assurance and Safety[1] confirms, they are essential to ensuring patient safety, service reliability and public confidence. They are also necessary for the calculation of budgets and investment plans. However, apart from work by Skills for Health[2], there are currently no accepted levels of competence[3] for those working in respiratory care. Furthermore, if we support the Roach[3] definition of competence, existing courses, apart from postgraduate medical training, are not assessed or validated against these holistic criteria, nor is the assessment of practising clinicians set up to assess performance.

The observation of the IMPRESS working party is that there are some nursing and medical colleagues performing high level care in COPD; there are also some who are providing sub-optimal care. Variation in referral rates for COPD from primary care to secondary care suggests differing levels of clinical confidence in delivering community-based COPD care and may reflect lack of awareness of the scale of the problem and hence low detection rates. In addition, there may be some nurses who are working, or are being asked to work, outside the boundaries of their competence. For example, a very recent paper by Upton[4] found 368 lead COPD nurses, 215 with an advanced role of whom *half* had no extended training programme. It is likely that these important findings are replicated in other settings[5].

Questions for commissioners: Who is accountable locally for ensuring that the workforce has the competence to deliver locally-specified respiratory care? Who takes responsibility for addressing any shortfalls in the short, and longer term?

Accreditation

Furthermore, the existence, or otherwise, of “accredited” practitioners may not be an appropriate standard for commissioners, because it has more than one form. Accreditation can mean a local check on standard training such as Child Protection. It can also mean academic accreditation, which is likely to be based on the candidate’s competence to argue cogently in a written submission. It can also mean approval by professional peers that the candidate is able to apply knowledge and

[1] Integrating and IMProving RESpiratory Care in the NHS
[2] British Thoracic Society (www.brit-thoracic.org.uk) and the General Practice Airways Group (www.gpiag.org)
[3] ‘ the state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of ones professional responsibilities’

demonstrate competence. IMPRESS proposes that the term ”accredited practitioner” whilst being useful in some circumstances is not an assured or necessarily robust guarantee of clinician performance.

Question for commissioners: Who has the competence locally to judge whether performance is satisfactory?

Lack of evidence

IMPRESS believes that the effectiveness of pulmonary rehabilitation in COPD supports the value of a multi-disciplinary approach to care. However, there is very little evidence about what skill mix is most effective in any aspect of respiratory care; therefore there are many variations in service provision. Whilst local experimentation and review is a useful approach to service improvement, IMPRESS has concerns about the wholesale implementation of unevaluated interventions – “the Award Effect”. For example, the Virtual Ward created by Croydon PCT has received significant interest from around the UK, due to its success in winning several awards for innovation, but no funding has yet been secured for a formal evaluation of the effectiveness of the scheme and therefore there is no peer-reviewed assessment available for review and comparison with other interventions.

Question for commissioners: what evidence are you using to judge the mix of skills and disciplines you require? Do you have a local clinical multi-disciplinary network to advise you?

Investment in training, education and Continuing Professional Development

IMPRESS advocates for sufficient investment in training, education and continuing professional development (CPD). Its observation is that there have been changes in how this is delivered in respiratory care in the last 18 months, and that at present, there is insufficient quality assured and appropriate investment. Historically, respiratory training across primary and secondary care has been subsidised by the pharmaceutical industry, but that is being reduced. University courses have also been reduced, due to commissioner frustrations at their lack of flexibility and a growing preference for work-based learning. Work-based learning has expanded, particularly in primary care to support the implementation of the QOF, but tends to be limited to QOF requirements and is not quality assured. IMPRESS recommends that there is an increase in training, education and CPD using whatever combination of providers and funding is appropriate in a locality so that fit for purpose work-based learning programmes can be developed, evaluated and allow assurance that clinicians trained in this way are clinically competent for the tasks they undertake.

Questions for commissioners: do you know what was spent last year on training and education in respiratory care? What do you expect to be spent this year? If the budgets are devolved to practices, how do you assure yourselves that the budget is allocated appropriately?

Roles and responsibilities for workforce development

Reorganisation of the PCT function as a performance manager, with an operational role only for its provider-arm, not for general practice, may accentuate the problem in some localities, leaving temporary confusion about responsibility for workforce development and challenges about how best to deliver it. In addition, whilst there has been a relatively stable primary care workforce, the average age of practice nurses, who provide much of the routine respiratory care in general practice, is now over 50 years. So, even if many of these nurses are trained and delivering high quality care, there is a need acknowledged by SHA Workforce Directorates for investment in the workforce that replaces them as they retire. This is also an opportunity to evaluate their role and effectiveness.

Question for commissioners: who is responsible for looking at the sustainability of the respiratory services?

Patient-centred care: new skills and new investment

It is important that the development of patient-centred care and the development of mutuality in the clinician-patient relationship is backed up by an analysis of clinical training needs and the delivery of appropriate training for existing clinicians and those in training that equips them with the communication skills and improvement methods to "co-create services" and "co-produce outcomes". This is in addition to the clinicians' need to maintain their clinical expertise and local knowledge of the health care community and needs of the population.

There are some particular difficulties in achieving fully engaged patients and clinicians in COPD from the current position in many localities where there has been no investment in services, evidenced by surveys such as the recent British Lung Foundation's Invisible Lives.[6] This can lead to patients and clinicians feeling very disempowered by the nature of the disease and often by their experience of care to date.[7] i.e. there is little use in offering choice if there is no choice.

Questions for commissioners: What discussions have you held about how to equip the system with the knowledge, skills and attitudes for delivering patient-centred care? How are patients involved in designing and delivering their care? What mechanisms exist for patients' feedback to clinicians?

The cheapest may not be best value

Ultimately, pricing a service, and comparing competing services, will depend on the mix of professionals in the service. Commissioners may require help to achieve an effective balance between cost and quality. The balance needs careful consideration as the range of quality service provided is large and it would not be in a PCT's interests to commission services that do not provide sufficiently robust quality assured care and integration with other local services.

Questions for commissioners: what evaluation do you have in place to monitor that changes in skill mix and workforce are leading to positive improvements? Note: IMPRESS will be producing a proposed evaluation framework.

Involve the respiratory network, request clinical leadership

Our NHS Our Future[8] also reasserts the importance of clinical leadership and local accountability. IMPRESS argues that commissioners, supported by public health teams, should work in partnership with respiratory specialists and local generalists to assess the health care needs of the community and the competence of the respiratory system locally, and to address the shortfalls through management, planning, training and mentoring. It also acknowledges that this requires respiratory specialists (primary and secondary care) to regard these functions as legitimate work for clinical leaders, and see themselves as more than expert case managers, who take responsibility for the quality of care delivered to their local community.

Question for commissioners: what are you doing to ensure that there is clinical leadership and engagement?

Here are the standards and principles we propose, which fit with the framework of the vision for the NHS, laid out in Lord Darzi's's interim report, Our NHS, Our Future[8] of a fair, personalised, effective, safe and locally accountable NHS.

Standards and principles of COPD competences

Effective care by competent professionals

Patients have a right to receive a personal assessment and to be treated by competent professionals who provide effective care attuned to them in particular. As people with COPD move along the care pathway from prevention through to palliation, they will require care of a standard set by guidelines, but also the support of knowledgeable, experienced, skilled and proficient practitioners who can provide and co-ordinate their care across different service and professional interfaces. A large part of this capability will come from individual professionals' recognition of clear boundaries and clear and accepted lines of accountability and expertise. Many people with COPD will have comorbidities and complex care needs and they should expect that the professionals they encounter can manage these or ensure appropriate referral to other specialists.

The multi-disciplinary team

The NICE COPD guidelines[9] recommend multi-disciplinary team working. Whist the evidence for multi-disciplinary working is based on expert opinion it would appear self-evident that with varying needs, patients may need the skills of different professionals at certain times. In addition, a later review by Singh[10] of the literature on long term conditions – not COPD specific - shows that there is good evidence that care from multidisciplinary teams in hospital can reduce the length of hospital stay and may reduce readmissions but this could be due to the intervention e.g. medication review or follow-up; it is not known which members of team make the difference. There is also good evidence that high quality primary care reduces hospital admissions and mortality as well as improving quality of life[11].

Care should be co-ordinated across the disease trajectory and it should be clear who is responsible for making which decisions Team members need to learn as individuals and as teams. Practitioners may have minimal involvement, medium involvement and maximal involvement in a patient's care but require the prerequisite knowledge and education for each level of involvement. These three levels of involvement for practice nurses have been set out by the GPIAG: http://www.gpiag.org/nurses/skills_level_set_180707.pdf

Integrated care

Despite limited published evidence about the benefits of integrated care between primary and secondary care or between health and social care for the management of long term conditions, the face validity would support it and policy direction is for better integration. It should improve the patient experience and reduce inefficiencies. IMPRESS would also argue that it is critical that patients have the right to both specialist advice for specialised problems and generalist advice for generalised problems since they offer complementary support to people with long term conditions. This is particularly true since many people with COPD have co-morbidities. IMPRESS would also expect that a patient should expect any competent professional to manage common problems to that condition. The new roles of community matrons and other care-coordinators have also been established to address the perceived need for improved integration and recognises that many patients have more than one long term condition. IMPRESS will assess the emerging evidence base with interest.

Patient centred care "nothing about me, without me" [www.IHI.org]

NHS England health policy is to make care for people with long term conditions more patient-centred: adding years to life and life to years. The aim is for co-creation of services with patients that meet their individual needs to live with a long term conditions, and for co-production of services. A recent review of the international evidence commissioned by the Picker Institute on patient-focused interventions[12] looked at the evidence for this policy. It concluded that personalised and tailored health information useful to the individual patient can improve outcomes; that shared decision-making between patients and clinicians in the forms of communication skills training for clinicians, coaching for patients, and patient decision aids improve the patient experience; and that self-management programmes can work, if they are long and intensive, and if combined with a personal action plan. It also confirmed that patients can make healthcare safer. IMPRESS wholeheartedly supports these findings, and also believes it is the role of the healthcare professional to educate and raise the expectations of people with COPD, which may be suppressed by lack of knowledge, guilt, or previous experience of healthcare.

IMPRESS recommends that there should be a system for eliciting and appraising patient feedback to clinicians about their performance. This is included in each of the standards below. We await the outcome of research on methods such as 360 degree feedback alluded to in the white paper on professional regulation.[1]

Equality and equity in access

There are a number of inequalities operating in the provision of COPD care. Access to diagnosis remains patchy within and between PCTs despite public health data identifying at a micro-level where patients might be at risk.[6] Access to expert services such as pulmonary rehabilitation is variable throughout the UK. As a patient's disease progresses they may require access to services such as palliative care that traditionally have not been available to patients without a cancer diagnosis despite evidence that patients with COPD have poorer health status and unmet need.[13] [14] Many patients are not screened for anxiety and depression[9] nor have their mental health symptoms actively managed. Yet there is evidence that people with severe COPD have higher levels of depression[15] and anxiety.[16] Work in Greater Manchester suggests people who have higher levels of anxiety are more likely to use unscheduled care.[17] Trained professionals are much more likely to identify psychosocial problems than untrained and would therefore identify those at risk earlier[18]. A significant number of people with COPD will have co-morbidities that also require care[19]. There is a correlation between smoking and lower social class and between certain ethnic groups. For example, up to 60% of Bangladeshi men smoke[20]. There continues to be worse access to appropriate healthcare for these communities. This means that people with, or likely to develop COPD, are more at risk of poorer access to services that would help improve their quality of life.

We believe all patients should have the right to:

- Preventative interventions ie smoking cessation
- Timely diagnosis that is documented and includes an assessment of level of disease severity
- To have their disease, treatments and treatment changes explained to them in a way they can understand and tailored to their information needs
- Evidence of good clinical assessment of physical, mental health and social care needs
- Documentation of treatment options in accordance with guidelines or outside guidelines with confidence and expertise
- Evidence of individualised care package
- Ongoing management by appropriately trained individuals
- Documented evidence of social support such as benefits, home adaptations, blue badges, referral to EPP or patient support groups

Standard 1
Patients should receive individualised care from knowledgeable practitioners experienced in COPD care.

Markers of Good Practice

- Evidence of an operational and agreed annual professional and managerial appraisal system across primary and secondary care that involves reflective practice, patient feedback and identifies a continuing professional development programme led by people with competence to make an appraisal
- Maintenance of a Competency Register or portfolio of learning.
- Evidence of effective communication and consultation skills [note that we are only aware that the MRCGP reviews performance].
- Evidence of positive patient feedback
- Clear clinical governance systems that ensure patient safety.

Standard 2

To ensure effective performance, COPD care should be delivered by a range of health care practitioners working as part of a multi-disciplinary team. Any mentally competent patient or member of staff should be able to name who leads the service.

Markers of good practice

- Evidence of a team with clear lines of accountability
- Evidence of continuing professional development for all team members
- Evidence of a supporting infrastructure for coordinated care, e.g. administration and information systems
- Diversity of team membership; staffing ratios and existence of learning / educational diaries
- Evidence of effective skill mix of team members
- Uni-professional and team learning and ongoing education
- Evidence of effective communication between the team
- Evidence of positive patient feedback
- Audit of effectiveness

Standard three

Integrated Care: patients should not see the joins, feel pulled in different directions, or be asked unnecessarily repetitive questions – their care should be seamless, continuous, appropriate and responsive no matter who provides the service and no matter how many co-morbidities the patient may have.

Markers of good practice

- Evidence of joint agreement on and delivery of COPD pathways
- Evidence of reliable, timely and expert communication between different health care clinicians.
- Establishment of "COPD Networks" encompassing primary, secondary and social care
- Evidence of positive patient feedback
- Co-ordinated care across the health district

Standard four

Patient centred care: patients must be active participants in securing appropriate, effective, safe and responsive care

Markers of good practice

- Evidence of effective communication with the patient and carer
- Provision of personalised, tailored information about COPD including prognosis, treatment options and how to get support to manage their condition
- Patient prompts, questionnaires or coaching cards to improve the effectiveness of the consultation
- Availability of patient decision aids
- Evidence of personal action planning with patients
- Evidence of local self-management programmes / pulmonary rehabilitation
- Evidence of positive patient feedback
- Easy patient access to medical records: some commissioners have moved to patient-held records or summaries familiar to maternity services and child health.

Standard five

Equity and equality in access

Markers of good practice

- Record of assessment and appropriate intervention or referral for people who smoke and are ready to quit
- Record of assessment of disease severity
- Referral to appropriate practitioners for review
- Knowledge of, and referral to/or use of services for people who find it difficult to read or understand spoken English; for people with a disability; or who have other problems accessing healthcare such as mental health problems and alcohol dependence
- Record of assessment of palliative care needs
- Evidence of positive patient feedback
- Evidence of carer satisfaction

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Links to further resources

IMPRESS http://www.impressresp.com

British Thoracic Society (BTS) http://www.brit-thoracic.org.uk/index.html

General Practice Airways Group (GPIAG) www.gpiag.org
ARNS http://www.arns.co.uk/pages/home.html

British Lung Foundation http://www.lunguk.org/

Asthma UK http://www.asthma.org.uk/

GPIAG papers on accreditation of practitioners with a special interest
http://www.gpiag.org/gpwsi/gpwsi_nm.php

GPIAG Basic skills for delivering high quality respiratory care by practice nurses.
http://www.gpiag.org/nurses/skills_level_set_180707.pdf

Skills for Health http://www.skillsforhealth.org.uk/page/

Education for Health http://www.educationforhealth.org.uk/

Respiratory Education UK http://www.respiratoryeduk.com/

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