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Respiratory Service Specification /COPD



Respiratory Outpatient Care

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- Representing primary care respiratory health needs at policy level
- Promoting best practice in primary care respiratory health through education, training and other services
- Supporting the development of primary care health professionals in respiratory medicine
- Facilitating and leading primary care respiratory research.

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Delivering respiratory care closer to home by improving the way respiratory outpatient care is provided

Executive Summary

- NHS policy requires commissioners to move care closer to home. This paper focuses on the respiratory care
 pathway, and, in particular, highlights the main opportunities and challenges in moving patients' care closer
 to home.
- The NHS Institute's (NHSI) work on Care Outside Hospital identifies four approaches to achieving a shift: integration, substitution, segmentation and simplification. This paper uses these approaches, giving respiratory examples, acknowledging that in practice, these four approaches are often combined.
- Transforming outpatient care may be regarded as a "quick win". However, done in isolation from reviewing the whole pathway there is the potential to destabilise or distort care provision. Many of the examples illustrate how clinics are just one element of bigger improvements.
- The objective should be to provide patients with the right care at the right time, reliably, by the professional(s) most competent to provide their care.
- This would usefully involve a better match between primary care providing routine care, and specialists providing specialist expertise and insight.
- It would also make the most of primary care generalists' skills in providing much needed co-ordination of care for patients with physical and psychological co-morbidities.
- It should be remembered that the most important step in a pathway is to ensure the person has the correct diagnosis and so is put on the right pathway; therefore time and effort should be spent developing and making available the right assessment and diagnostic services, particularly for patients with co-morbidities.
- There should therefore be a distinction between the service required for accurate and early diagnosis, and that required for follow-up care.
- There are many opportunities to provide patient-centred care, which is closer to patients' homes for people with asthma and Chronic Obstructive Pulmonary Disease (COPD).
- Decisions about location and level of specialism should be kept separate: a consultant can work in a community setting.
- The shift should be driven by an ambition to improve the personalisation of care, and to deliver it closer to home, not by a drive for savings.
- The key issue for many patients is about more flexible access timing and mode of consultation with a healthcare professional of their choice. Currently primary care can normally offer more flexibility than secondary care and enables patients to choose what suits them at that point in their lives.
- Planning requires local stakeholder input. It should consider what has worked before (although recognising that there may be little data available about this, such as the impact on asthma care of the shift to primary care), local audits of referrals and what patients want.

- Successful service redesign needs the co-operation of clinicians, managers and patients across service boundaries.
- Commissioners must assess the competence of the local workforce to deliver any shift and have a clear set
 of indicators to judge its effectiveness. Local clinicians, particularly local specialists, have a responsibility to
 advise on this to support the development of skills across primary care, and to cooperate with evaluation. Commissioners should consider the opportunity for some specialists to actively educate and develop the local
 workforce. IMPRESS has proposed some standards of competence for COPD:
 www.impressresp.com/Commissioning/ProposedstandardsforcommissioningCOPD
 Service/tabid/73/Default.aspx
- The health community has a responsibility to engage patients in any discussion about changes and to ensure they are reassured that the purpose of the change is to improve their experience of care.
- In the absence of national guidance on coding and payment, commissioners will need to make local agreements with their NHS providers about innovative approaches such as telephone consultations.
- There is limited evidence to date about the use of telemedicine but telephone and IT solutions are an increasing part of life and are therefore are becoming an expectation of service users. In this rapidly moving area, commissioners need to build flexibility into their plans and focus on outcomes not processes.
- It is important to understand the baseline for activity using routinely available data. If campaigns to identify those with COPD who are not yet diagnosed are successful, it is likely that this will require an increased level of intervention such as smoking cessation, and prescribing costs and care.
- The lack of national diagnostic coding of out-patient activity means that baseline data on which respiratory
 patients are currently receiving out-patient respiratory care is missing and makes planning new services more
 difficult.
- Models of care are changing all the time, and therefore commissioners should work with local clinicians and managers to develop a system that suit suits the local situation. In addition, IMPRESS will update this, and its other guides, as the evidence emerges.

Delivering respiratory care closer to home by improving the way respiratory outpatient care is provided

1. Introduction

NHS policy made operational in the 2008/09 Operating Framework for the NHS requires commissioners to move care closer to home. This paper focuses on the respiratory care pathway, and, in particular, highlights the main opportunities and challenges in moving patients' outpatient care closer to home.

To set a framework for thinking about this, it draws on the conclusions of the NHS Institute's (NHSI) work on Care Outside Hospital http://www.institute.nhs.uk/care_outside_hospital/care/care_outside_hospital.html

One of its key reports, *Getting the basics right: Final Report on the Care Closer to Home: Making the Shift Programme*¹ identifies four approaches:

- 1. Integration (between primary and secondary health care and social care)
- 2. Substitution:
 - a. Location
 - b. Skills
 - c. Technology
 - d. Model from medical model to supported self care/co-creation/co-production model
 - e. Organisational (eg by private or voluntary sector)
- 3. Segmentation (of patients with similar needs)
- 4. Simplification (of pathway by reducing handoffs. This might also include frequency of follow-up and review).

This paper will use these approaches, giving respiratory examples. The examples are not exhaustive but are included to illustrate what is possible. IMPRESS welcomes further examples, which it will disseminate further. It is also the case that in practice, these four approaches are often combined.

Firstly, there are some general points to make.

2. Care pathways

Transforming outpatient care may be regarded as a "quick win". However, there may be little point in doing it in isolation from reviewing the whole pathway. There has been much written on pathway redesign. There is a lot of good evidence for redesigning some parts of the pathway e.g. options for admission avoidance and early discharge in respiratory care (particularly COPD). There is less good evidence for some other parts of the pathway. This paper does not cover this ground except to say that IMPRESS recommends that the mapping of the current pathway, and its redesign should involve a network of patients, primary and secondary care clinicians, pharmacists, commissioners, social care, public health and finance staff. Local clinicians with a special interest in respiratory disease can provide more information about the evidence.

The objective should be to provide patients with the right care in the right place, at the right time, reliably, by the professional(s) most competent to provide their care. This would usefully involve a better match between primary care providing routine care, and specialists providing specialist expertise and managing severe disease. It would also make the most of primary care generalists' skills in providing much needed co-ordination of care for patients with comorbidity. The Map of Medicine http://www.mapofmedicine.com/what_is_the_map.php offers NHS staff a number of evidence-based COPD pathways (including links to the Skills for Health work on competences). In addition, there are a number of examples on NHS websites, including the NHSI report of a case study in Derbyshire to reduce COPD admissions by 15 – 20% in its report *Beyond Projects*.² This draws out a number of the process issues involved. However, it should be noted that the most important step in a pathway is to ensure the person has the correct diagnosis and so is managed according to the right pathway. Time and effort should therefore be spent in developing the right assessment and diagnostic services, particularly for patients with co-morbidities to minimise the number of visits they need to make. Whole systems thinking is needed to prevent patients who follow more than one pathway making multiple journeys to different locations.

¹ Ham C, Parker H, Singh D, Wade E. University of Birmingham Health Services Management Centre May 2007.

²Beyond Projects. Case Studies from the Care Closer to Home: Making the Shift Programme downloadable from:

http://www.institute.nhs.uk/option,com_joomcart/Itemid,26/main_page,document_product_info/products_id,292.html

3. The 18-week wait

In some specialties such as orthopaedics and surgery this target has led to the transformation of outpatient services. However, it has largely left respiratory care untouched, as most care is non-elective and thus already delivered within 18 weeks. The only area where this might be a key driver is in sleep apnoea services. However, if achievement of the 18-week wait is a target, then the No Delays tool offered by the NHS Institute is very helpful: http://www.institute.nhs.uk/no_delays/introduction/no_delays.html

In addition, respiratory care will be affected by other acute sector reorganisation and the outpatient tariff will encourage an analysis of how much specialist team time is spent on first appointments and how much on follow up care. The financial incentive for acute trusts is to increase the proportion of first appointments whilst reducing follow up appointments, and this is probably an appropriate driver of change, since specialist skills and facilities will be particularly needed during the diagnostic phase of care.

4. Data collection and Payment by Results (PbR)

Historically outpatient coding has been extremely unhelpful in terms of planning alternative ways of providing the service. It has not allowed analysis by reason for referral, patient diagnosis, or, in some cases, even speciality. Therefore any work on changing the model of care will require collaboration from primary and secondary care on data collection and analysis.

Furthermore, PbR does not yet recognise certain activity for payment, such as telephone consultations in secondary care (with a referrer or with a patient) which is an important barrier to change. This will require local negotiation until the tariff offers a standard form of coding and payment. IMPRESS has made a number of submissions to the PbR team about this.

It is also worth noting that in some acute hospitals, a proportion of the activity may be nurse clinics and physiotherapy clinics, and this activity may not be counted or costed. However, there are now codes available to capture this information (HRG version 4.3 available to download as Appendix 2 of the IMPRESS Jargon Buster: http://www.impressresp.com/JargonBuster/tabid/63/Default.aspx

5. The "shift dividend" – why choose respiratory care?

The NHS Institute's work has demonstrated that commissioners do not always make the best selection of project(s) to achieve what is known as the "shift dividend". That is, will the change be an improvement for patients without introducing any significant inefficiencies elsewhere? IMPRESS believes that respiratory care affords many opportunities for doing things better, particularly for routine follow-up care. Breathless patients who have trouble getting around would surely benefit from care in easily accessible settings (which may be provided by the local acute trust). However, the motivation must be to deliver high quality, patient-centred care, not just doing things more cheaply. Cheap care is frequently ineffective care, consuming fewer resources initially but building up bigger problems which are more expensive to sort out later or reducing quality of life.

So, it is important to be clear what improvement is desired and how resources need to be reconfigured in order to attain that improvement. A focus on delivering patient-centred care will have the twin benefits of engaging clinicians in care design and building their trust that the change is worth the upheaval.

Local needs assessment exercises, much of which can be derived from routine data, and use of the Opportunity Locator from the NHS Institute http://www.institute.nhs.uk/opportunitylocator may also generate analyses of respiratory conditions currently managed in in-patient settings that might shift to specialist outpatient care, if specialist resource can be freed up by the shift of routine care. Examples include pneumonia, pneumothorax, airflow obstruction and pulmonary embolism/DVT.³

Patients with co-morbidities

From a patient's perspective, one of the real advantages of designing a service that offers true patient-centred care would be that those who have several long term conditions, such as COPD and heart failure, might receive coordinated advice and treatment. Uncoordinated care remains a frustration for many such patients, requiring a set of appointments for each condition.

³ BMJ 2008; 336: 4-5

Asthma care

Very little routine asthma care is now provided by secondary care, and in general practice, is largely provided by practice nurses. Increasingly, this trend includes routine COPD care, and the General Medical Services Quality and Outcomes Framework includes both asthma care and COPD care. This, it could be argued, is a good example of a shift dividend. There is some evidence of a reduction of unscheduled appointments⁴ although the reasons are not clear and there remain significant numbers of attendances at A&E and other urgent care facilities that are not fully explained and still need improvement. Asthma is very prevalent and affects children as well as adults, therefore attention to asthma is important. If commissioners prioritise other long term conditions that cause use of more bed days, assuming asthma care is optimal, then people with asthma that is not controlled (current data suggests 45% of the population with asthma exhibit sub-optimal control) stand to suffer further disadvantage and create inequalities between people with different long term conditions.

It would be useful to look at the experience of managing asthma care in the community before turning to other respiratory conditions.

Primary care flexibility

In addition, it is important to understand how patients' needs for flexible care may now be met in primary care. This raises their expectation about the rest of the health system and frustration at systems that do not allow them to arrange the appointment when they need it. So, many practices now offer alternative appointments (different modes of consultation, different professionals, same day appointment with any doctor or an advance appointment with own GP). Patients may be able to e-mail the doctor they saw the week before to clarify a point, or feedback some information. They may be able to choose to convert their face-to-face appointment to a telephone call if all is well, or vice-versa if a problem has arisen. Therefore these choices need to be available to patients.

The issues about coding and payment for hospital appointments such as telephone appointments need resolution to enable the flexibility patients want. However, it is possible to negotiate local agreements in the absence of national tariffs.

6. How to make shifts

NHSI recommends dedicated project management; a clearly defined project, outcome and success criteria; organisational leadership; a supportive culture in which shifts can be attempted; involving the right levers and right people, particularly clinicians and aligning their visions and needs for a sustainable service; training (management); measures of progress; sufficient time; and arrangements for sustaining and "scaling up" shifts.

7. Different approaches, opportunities and challenges

The following pages give examples of the different kinds of shift possible in respiratory care, using the categorisation of integration, substitution, segmentation and simplification.

a. Integration (between primary and secondary health care and social care)

For best results it is not always possible to isolate outpatient care. These examples show how bed days can be reduced by provision of flexible multi-disciplinary team consultation in different locations.

Integration: Example across acute and non-acute care

In Wigan, there has been a review of the whole COPD service, led by a hospital consultant who now holds the role of Consultant in Community Respiratory Medicine, Dr Roger Wolstenholme, one of two such roles in England at present. The service includes a nurse-led acute assessment unit, and a nurse-led community service that has been running since 2000. Early achievements were:

- 3,189 bed-days saved during the first three years of the acute assessment service
- Average length of stay reduced from seven days in 1997–98 to two days by 2001–02
- Fewer COPD patients attending consultant-led chest clinics. Patients having a consultation with the community respiratory consultant are seen in a hospital clinic. This setting is chosen as it currently provides what these patients need (including access to imaging, cardiac investigations, input form other physicians).
- Increased satisfaction of patients, secondary care colleagues and GPs
- Individualised treatment and care plans for patients
- More rational use of oxygen and drugs
- Pulmonary rehabilitation set up for 1,500 patients
- Very positive results from patient, doctor and nurse surveys.

⁴ Fleming DM, Sunderland R, Cross KW, Ross AM. Declining incidence of episodes of asthma: a study of trends in new episodes presenting to general practitioners in the period 1989-98. *Thorax* 2000; 55: 657-661

Integration: Example across health and social care

In Huddersfield, a community matron with a high skill level in respiratory care runs the respiratory community clinics to provide holistic care in the clinic and in the community. Community matrons are trained to integrate with community physiotherapy and occupational therapy as well as social services so that patients' non-medical needs are also addressed.

Integration: Example – across primary and secondary care (London)

In line with evidence⁵ many localities already provide early discharge teams, Acute Respiratory Assessment Services (ARAS) services and intervention services. These are often led by nursing or physiotherapy teams with medical support from local clinicians. The Chronic Respiratory Support (CRS) team provided by the Whittington Hospital, North London, (winner of Hospital Doctor Award in 2006) is an example of a hospital-led initiative, working across into the community. It was developed using local data to identify and focus on the small number of patients with repeated or prolonged admissions who were responsible for most bed days. CRS, a team of five (respiratory nurse specialists, respiratory physiotherapists and an occupational therapy assistant) provide supported self-management using a telephone help-line and home visits and pulmonary rehabilitation in the community with psychologist input. CRS has saved ~1000 bed days annually for each of the last 5 years and has substituted care at home for follow-up appointments in clinic. The CRS team are supported by the respiratory consultants and work closely with a consultant cardiologist, community palliative care team and the London Ambulance Service.

Integration: Example – across primary and secondary care (Salford)

The Salford Integrated Respiratory Service is moving care closer to home and streamlining the patient journey by providing ongoing clinical support to wider health care teams. It has established a community COPD clinic run by a consultant respiratory physician and respiratory nurse consultant with access to advanced diagnostics via service level agreements with its hospital trust and multi-disciplinary team (MDT) support from primary and secondary care (pulmonary rehabilitation, home oxygen service, physiotherapy, occupational therapy, psychology service, palliative care service). Integrated referral pathways and protocols have been developed in collaboration with primary care commissioners and secondary care providers so that patients can be referred from both primary and secondary care. The clinic has the capacity to see 240 new and 240 follow up patients a year. The service also developed a COPD MDT that offers primary and secondary care clinicians the opportunity to discuss physical, psychological and social issues face to face or remotely by e-mail reducing unnecessary referrals. Each general practice has also been allocated a named member of the team as their key contact for more urgent problems. The MDT has particularly enhanced the care delivered by community matrons and active case managers by increasing their skills and knowledge. The service also introduced telehealth to case managed patients with complex/severe COPD which is jointly monitored by the integrated respiratory team and the case manager. This integrated approach has led to a 10% reduction in unscheduled admissions in the first 9 months with a cost saving of £170,000.

Integration: Example, across primary and secondary care (Southend)

An integrated hospital and community-based intermediate care service for the prevention and early discharge for patients with COPD produced length of care, readmission and mortality rates similar to those achieved in the randomised controlled trials.⁶ In addition Southend has shown that an integrated home oxygen service between secondary and community care, saves £130,000 per year on oxygen tariffs.⁷

Integration: Example, across the whole system

Breathing Space in Rotherham is a new, whole systems community-based COPD service across local government, the local hospital and primary care trusts. It has been created from a £12m investment mainly from the Coalfields Regeneration Trust. Nurse Consultant Gail South leads the service. It incorporates a state of the art building, rehabilitation/respite facilities including 20 beds, It is staffed by a team of specialists nurses, education co-ordinator, clinical specialist physiotherapists and occupational therapists managing a team of support workers. A comprehensive evaluation framework has been developed in partnership with Sheffield University's public health research department (SCHARR). For more information please see its dedicated website:

http://www.rotherhampct.nhs.uk/breathingspace/us.html and for detailed and ongoing evaluation see http://www.rotherhamhealth.nhs.uk/healthprofessionals/BreathingSpace/evaluation.asp

Integration offers the opportunity to examine the current pathway of care across primary and secondary care and to modify them. This provides exciting opportunities to improve care for respiratory disease in the whole community.

⁵ British Thoracic Society. Intermediate care – Hospital-at-home in chronic obstructive pulmonary disease: British Thoracic Society guideline. *Thorax* 2007; 62: 200-210

⁶ AG Davison, M Monaghan, D Brown, CD Eraut, A O'Brien, K Paul, J Townsend, C Elston, L Ward, S Steeples and L Cubitt. Hospital at home for chronic obstructive pulmonary disease: an integrated hospital and community based generic intermediate care service for prevention and early discharge Chronic Respiratory Disease 2006; 3: 181–185

⁷ Deeming C, Ward L, Townsend J, Ganeslingam K, Ansari SO, Powrie D, Davison AG. An integrated home oxygen service saves £130,000 in one year on home oxygen tariffs. *Thorax* 2008; 63: 566.

b. Substitution

i. Substitute location

This model has been used since the days of GP fund holding. It normally involves a hospital consultant travelling from the hospital to run clinics in the community, or it can be combined with a downwards shift in the level of specialism – for example, the patient is seen by a practitioner with a special interest. Hilary Pinnock's study⁸ has summarised the evidence.

The evidence

As fundholding was disbanded amidst concerns about inequity of care provision, two systematic reviews considered the advantages and disadvantages of outreach clinics in order to inform PCOs taking over responsibility for commissioning care.⁹¹⁰ UK-based surveys and qualitative studies suggested that, although outreach clinics were appreciated by patients for their convenience and offered opportunities for improved GP–specialist communication, they were generally expensive in terms of consultant time and costs.¹⁰ Similarly, a Cochrane review of international intervention studies showed that simply exchanging the hospital outpatients for a primary care clinic improved access, but had no effect on health outcomes.⁹ However, outreach services that included collaboration with primary care or educational interventions facilitated implementation of guidelines and improved health outcomes, especially in rural and disadvantaged communities. Commentators concluded that although outreach clinics were unlikely to replace outpatient clinics in their original format, the policy for "community resource and treatment centres" would promote specialist care provided from well equipped 'polyclinics' and prompted speculation that in time PCOs would employ their own consultant staff.¹¹ More recently, Black has proposed a form of community medical centres run by partnerships of primary and secondary care physicians offering a 'hybrid' service.¹²

Unless the patient requires complex tests, in which case it may be better to hold the consultation in a location where the test facilities exist, a community setting is probably more acceptable to the patient. It is likely to be easier to park, is probably closer to home, and in a more familiar, smaller-scale setting that may be less intimidating for the patient.

During the same visit it may be possible for the patient to connect with the other members of the primary care team who manage other aspects of their health. It will only work if there are planned opportunities for the consultant to work as part of the primary care team, sharing their knowledge and expertise, building relationships and understanding more about the community that their hospital serves. It will be least effective if all that happens is a re-location of the consultant to a different office. An additional benefit for the system may be lower 'did not attend' rates. Although hospitals have worked hard to reduce these, they may still be higher than those of general practice, which, typically are no more than 5%. So, *as long as* the practice organises appointments to achieve a critical mass of patients, the clinic has the potential to add value to patients, staff and the health system.

However, a general practice may also not be the most appropriate location. If the aim is to improve accessibility, it may be better to start by asking **"where are the people?"** rather than "where is there space for a clinic." This might encourage creativity. The NHS Institute has produced a number of good practice examples. See Clinic To Go.¹³

In Salford, June Roberts¹⁴ and her colleagues made decisions on where to place the consultant-led community COPD clinics (see above example of integrated primary and secondary care), pulmonary rehabilitation in community settings, and a home oxygen assessment service from an innovative needs assessment process. This used Read-coded templates that collected data automatically from GP computer systems and combined it with QOF, public health, socio-economic deprivation and Hospital Episode Statistics (HES) data to create a city-wide COPD register. They then mapped COPD outcomes (QOF prevalence, COPD severity by lung function, hospital admissions and length of stay) by individual practice and PBC commissioning group to identify areas of greatest need and located services accordingly.

⁸ The process of planning, development and implementation of a General Practitioner with a Special Interest service in Primary Care Organisations in England and Wales: a comparative prospective case study by Hilary Pinnock, Guro Huby, Alison Powell, Tara Kielmann, David Price, Sian Williams, Rebecca Rosen, Aziz Sheikh.

⁹ Cochrane review of international intervention studies Gruen RL, Weeramanthri TS, Knight SE, and Bailie RS. 2003. Specialist outreach clinics in primary care and rural hospital settings. *Cochrane Database of Systematic Reviews* 4

¹⁰ Powell J. 2002. Systematic review of outreach clinics in primary care in the UK. Journal of Health Service Research and Policy 7: 177-183

¹¹ Gillam S. 2001. Outreach clinics in the new NHS: not yet the end of out-patients. British Journal of General Practice 51: 261-262

¹² Black A. 2006. *The future of acute care.* NHS Confederation.

¹³ Downloadable from http://www.institute.nhs.uk/care_outside_hospital/care/see_what_others_have_done.html

¹⁴ Roberts and Bakerly Benchmarking COPD across an inner city primary care organisation Thorax 2007 62 suppl III S134

In a **rural setting** community hospitals may be an appropriate location. Services such as pulmonary rehabilitation can be provided alongside clinics and perhaps in-patient care. Nurses will be exposed to specialist expertise that will help to develop their skills. Polyclinics/primary care resource centres and mobile units may also become suitable locations.

If a patient receives care from a multi-disciplinary team, they may also be receiving care at home, and therefore their **own home** may be the most suitable location to provide individualised advice and care.

Some practice-based commissioning groups have considered hiring a named hospital specialist directly under contract (rather than a hospital department contract). This supports the building of relationships but potentially creates a risk of increasing inequalities of access, if that practice takes more than its fair share of the specialist resource. If an external specialist is hired who does not have a relationship with the local hospital, there is the risk of fragmentation of care and potential loss of goodwill, relationships and social capital in the local health system.

The requirement for flexible access for patients means that a change in location, mode of delivery and possibly change in skill-mix may need to go hand in hand.

ii Substitute skills

The key determinant of any substitution is that the patient should have access to professionals competent to meet their needs (see the IMPRESS guidance for commissioners on respiratory competences:

http://www.impressresp.com/Commissioning/tabid/57/Default.aspx) This may require a team approach rather than just the substitution of one practitioner for another. If new services are commissioned to meet a specific specification, there is an opportunity to be creative in recruitment and training. That is, to focus on assessed competences, rather than purely on qualifications or, particularly in nursing, assumptions about what a job title means. An example of this is spirometry measurement. It is possible to train someone to perform the test who does not have a professional qualification.

However, IMPRESS reinforces the need for early and accurate diagnosis. Patients should be assured that they will encounter professionals with appropriate knowledge and competence to make an assessment and diagnosis and to be referred if necessary to a more specialist team.

IMPRESS recommends the local agreement of referral criteria to raise issues of competence. See Thorax 2008;63(Suppl I):i1–i16. doi:10.1136/thx.2007.087627 available for download at: http://www.brit-thoracic.org.uk/IMPRESS/ClinicalDecisionMaking/tabid/275/Default.aspx

There are, therefore, probably more examples of skill mix substitution for follow up care:

Substitute skills: Example

In Thetford the GPs with a Special Interest (GPwSI) in respiratory medicine have involved the specialist respiratory nurse and the local consultant to put together a COPD care pathway that will work across primary, intermediate and secondary care. The GPwSIs aim to use the specialist respiratory nurses from the local hospital to run the clinic and see patients in their own home post discharge and help with patients who have been put on long term oxygen therapy (LTOT). Assessments will take place in a community clinic.

Substitute skills: Example

In Derby City and South Derbyshire, patients who are medically fit for discharge from hospital are referred for "active follow up" by the PCT community COPD specialist service. Patients are seen in a community clinic or in the patient's home within 4 weeks of discharge. This is separate from the early discharge service, although there are good links between the services. The hospital consultants also occasionally refer patients to the community team for more routine follow up who do not need specialist medical input. As with many of these schemes, referral levels are not consistent due to the turnover of junior medical and nursing staff on the wards. Therefore there is a need for continual awareness raising and education of hospital staff about the services from which patients would benefit and to which they could be referred.

There are also many examples of nurse-led oxygen assessment services.

It is also important that the **patient is informed about the reasons** as patient feedback suggests that some patients regard the changes as driven by financial cut-backs and worry that they will be offered poorer care as a result.⁸

Substitute technology

Technological solutions may offer new ways to provide follow up care. They cannot be a substitute for first appointments and diagnosis. There are already examples of the use of telephone consultations both in primary and secondary care. In primary care these are well used, and there is an efficiency gain for the patient and the GP. In secondary care, the telephone consultation might be with either the referring GP or with the patient. Both could significantly improve the patient experience, but there is no national tariff and therefore no incentive unless there is a local agreement on coding and payment. The local agreement may need to differentiate between a consultation, and the feedback of test results that might even be done by texting. There is no national guidance about use of mobile phones in terms of confidentiality and legality¹⁵, therefore confidentiality issues need to be overcome.

Patients want flexible access. Therefore face-to-face, telephone and email consultations should be part of a care pathway, depending on the patients' need at that time. It would not, for example, make sense to the patient to hive off "telephone follow-ups" as a separate contract, without recognising the loss in terms of their connection to a whole pathway of care. Frameworks such as Degeling's support zone¹⁶ and Kennedy's whole systems approach¹⁷ emphasise that care for long term conditions must incorporate flexible and structured support to enable patients to self-care.

Texting patients with results and reminders is also helpful to reduce the number of appointments booked to give results, and also to improve the uptake of clinic slots.

PACS terminals at "spokes" of a hub and spoke system would enable clinicians to review previous X-rays.

The Care Services Improvement Partnership has a website on telecare beyond telephone consultations **http://icn.csip.org.uk/telecare/** It includes, for example, a factsheet of the evidence for telecare dated November 2006.¹⁸ Since it was written, there has been a systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions.¹⁹ 8,666 studies were assessed. The review included 68 randomized controlled trials and 30 observational studies with 80 or more participants. Professor Barlow and his team concluded that: "the most effective telecare interventions appear to be automated vital signs monitoring (for reducing health service use) and telephone follow-up by nurses (for improving clinical indicators and reducing health service use). The cost-effectiveness of these interventions was less certain. There is insufficient evidence about the effects of home safety and security alert systems. It is important to note that just because there is insufficient evidence about some interventions, this does not mean that those interventions have no effect". For example telemonitoring might come to the fore for early identification of loss of control coupled with a mechanism to put in place an intervention to prevent deterioration and thus potential hospitalisation.

Virtual clinics, where test results and other information are reviewed by an expert without the patient present is another model that can be used either with other professionals as an educational initiative, or as an efficient way of processing information if there is no further benefit in the patient attending.

Substitute technology: Examples

There is little evidence yet about telecare and telemedicine in respiratory care. Most work is at a pilot stage and has not published evaluations. For example Asthma UK is funding a mobile technology trial at the moment. There are no randomised controlled trials (RCTs) published, and so it is important to explore the evidence-base before implementing any telemedicine scheme.

There is a telemedicine project in Kings Lynn offering practices virtual web-based reviews of registered patients diagnosed with asthma and COPD. Practices give permission for a company to analyse their anonymised data, and automatically update and annotate the practices' records. **http://www.optimumpatientcare.org/audit/audit.html**: There is also a specific computer-based tool, the DOSE index, to assess disease severity and provide simple guidance for management²⁰: **http://software.hits-uk.com/demo/copdfast**/

¹⁵ Pinnock H, Slack R, Sheikh A. Mis-connecting for health: (Lack of) advice for professionals on the safe use of mobile technology. Qual Safety Health Care 2007; 16: 162-3

¹⁶ Degeling P, Close H, and Degeling D. 2006a. Re-thinking long term conditions: A report on the development and implementation of co-produced, year-based integrated care pathways to improve service provision to people with long term conditions. Durham: Centre for Clinical Management Development.

¹⁷ Kennedy A, Rogers A, and Bower P. 2007. Support for self care for patients with chronic disease. British Medical Journal 335: 968-970

¹⁸ http://www.cat.csip.org.uk/_library/Telecare/CSIP_Factsheet_Telecare_Evidence_13_November_2006.doc

¹⁹ James Barlow, Debbie Singh, Steffen Bayer and Richard Curry. Tanaka Business School, Imperial College London, UK. Journal of Telemedicine and Telecare 2007; 13: 172–179. http://www.rsmpress.co.uk/jtt.htm

²⁰ Jones R, Hyland M, Harding1 S, Price D. The derivation of a new index of severity for COPD patients, the DOSE index: MRC dyspnea scale, airflow obstruction, smoking status and exacerbations. Abstract 1601 European Respiratory Society 2007 and Jones R, Chavannes N, Kida K, Donaldson G, Hyland M, Price D. The DOSE index predicts quality of life, health care consumption and mortality. Abstract 1602 European Respiratory Society 2007.

There is a telehealth project in Kent led by the County Council (KCC), begun in 2005, involving 250 patients and under evaluation. The patients have, typically, a range of self-monitoring devices covering four main functions, depending on each individual's particular condition: blood pressure; weight; blood glucose; and pulse oximetry. There is an electronic hub that patients use to upload their readings each day and receive messages and advice back from their nurse. The data is then sent to the clinical team via a secure web link. KCC uses its own servers for security. The system is configured remotely and what the patient sees on his or her monitor is tailored to their individual requirements. There has been significant learning about the competences required by staff. One outcome has meant that of six telehealth patients who recently died, four died in their own homes and only two had a hospital admission in the last year of their lives. Kent, Cornwall and Newham are the three sites for the Department of Health "whole systems demonstrator programme" on telehealth. See

http://www.kent.gov.uk/SocialCare/health-and-wellbeing/telehealth/

The American Lung Association offers patients a decision-support tool using a detailed self-completion questionnaire that helps patients understand their treatments, side effects, and provides questions to ask their doctor, and personalised, evidence-based reports:

https://www.lungprofiler.nexcura.com/Secure/Toolbox.asp?CB=26270&WizardNameId=1

Sheffield PCT has introduced telehealth to support patients to monitor their health in their own homes and claims to have significantly reduced hospital admissions and length of stay. High patient, carer and staff satisfaction has been reported – patients report it has improved their confidence and control of their condition and staff say it has improved their time management and prioritisation of patients. To view the video, click:

http://www.healthexec.tv/cgi-bin/details.pl?action=pre&id=461 (there is a registration page to complete first).

Telemedicine has been used for surgical opinions in lung cancer patients. Patients were discussed between the secondary care centre in Southend and the tertiary centre in London. The patients did not have to travel the 65km to the cardiothoracic centre to be assessed, the mean time to have surgery was reduced and the resection rate increased. Other non-malignant conditions were also discussed. In effect this brought the medical expertise closer to the patient's home.²¹

Whilst telephone consultations in primary care and electronic links to community hospitals are now common practice in more rural areas, the use of telephone consulations in secondary care has been constrained by the lack of nationally agreed tariff. However, there is some evidence of its efficiency.²²

Information for patients is available from many online sources: NHS Choices: (www.nhs.co.uk; www.patient.co.uk) which offers on-line access to huge amounts of reasonable patient information that can be printed in a GP surgery as well as given as a link for those with computers at home (the information is regularly checked by Asthma UK http://www.asthma.org.uk and British Lung Foundation http://www.lunguk.org), and the British Thoracic Society (http://www.brit-thoracic.org.uk).

iv. Substitute organisation (eg NHS by private or voluntary sector)

There have been some recent examples of community-based respiratory care being contracted out of the NHS.

Example

As part of a market testing exercise, Somerset PCT working with its commissioning group and local patients, tendered the provision of a new county-wide community-based COPD service, to complement existing primary and acute care services, and awarded it to a local GP-led team that set up a private company backed by a company with experience in nurse-led community services. IMPRESS has produced a commentary on this: http://www.impressresp.com/Commissioning/tabid/57/Default.aspx

v. Substitute model from medical model to supported self care/co-creation/co-production

The Next Stage Review published its primary care strategy on 3 July 2008 which sets a target of every person with a long term condition having a personal care plan by 2010. In addition, there will be pilots of personalised budgets. Therefore the policy direction is clearly supportive of models of self care where patients "co-produce outcomes" with their healthcare professional carers. A pre-requisite for this is that the patient is supported to understand their disease, the medications available, how to use those medications, how to monitor their condition and when to seek help.

 ²¹ AG Davison, CD Eraut, AS Haque et al. Telemedicine for Multidisciplinary Lung Cancer Meetings. J. Telemed Telecare 2004; 10: 140-143.
 ²² Roberts NJ, Partridge MR. Telephone consultations in secondary care. Resp Med 2007; 801: 1665-

Example

There are no standardised packages of education or comprehensive self management advice available for patients with COPD. A project based at Coventry University and the University Hospitals of Leicester NHS Trust is exploring the value of an independent, standardised self management for patients with COPD (SPACE, Self management Programme of Activity, Coping & Education) in both primary and secondary care settings. The development of the manual was funded by the British Lung Foundation and has the Plain English Crystal Mark award. The manual was developed with patients and contains structured advice on, for example, medication, activity and exercise, breathing control and exacerbation management. After an initial assessment the manual is introduced to the patient by a trained health care professional. For evaluation of the clinical trial follow up visits are scheduled. There is no expectation of follow up visits by the health care professionals, just telephone contact to encourage adherence. For further information please contact Sally Singh (s.singh@coventry.ac.uk).

Example

The Health Foundation, as part of their wider Co-Creating Health initiative, is facilitating and supporting a co-creating health project in COPD in Cambridge and Kilmarnock, using the model of agenda setting, goal setting and goal follow-up. It is currently in the early stages but should useful information on what might work for respiratory patients.

Example

In Australia, there has been a highly innovative implementation of research on the management of asthma through the use of breathing exercises, conducted by researchers and doctors at Sydney's Woolcock Institute of Medical Research and Melbourne's Alfred Hospital, which was published in the August 2006²³ edition of *Thorax*. The results of this study showed that people with asthma who undertook regular breathing exercises reduced their preventer medication levels by up to half and reliever use by up to 86%. The study suggests that breathing exercises as a first-line symptom treatment can help to reinforce the message of relaxation and self-efficacy and provide a deferral strategy for beta-agonist use. A 40 minute video that demonstrates breathing exercises designed to help reduce the use of asthma inhalers is now available to the general public for free from the Cooperative Research Centre (CRC) for Asthma and Airways **www.asthmacrc.org.au**. Two different groups of breathing techniques are demonstrated. One set is for practicing daily and one set is for relief of asthma symptoms. The research showed using either type of exercise was effective in markedly reducing the use of reliever medication. Asthma UK is undertaking similar research in UK populations.

c. Segmentation (of patients with similar needs)

One outcome of pathway mapping work is to identify which queues can be reduced by combining them, so that people with similar needs for health services are put into one queue. The evidence from the NHS Institute shows this is both fairer and more efficient. However, the mapping work may also identify groups of patients who require a separate pathway. For example, they may not speak English, they may have a tobacco dependency, or they may have mental health needs that require a different intervention.

The segmentation might be symptom based. For example, there are a few examples of breathlessness clinics although it appears that difficulties in sharing resources between cardiovascular and respiratory services have often limited their development. A paper by Maher and Hemming²⁴ concluded that another reason that breathlessness is not managed optimally may be insufficient nursing knowledge of related anatomy and physiology of breathlessness. Their study concluded breathlessness is one of the commonest symptoms experienced by people receiving palliative care. However, misunderstanding of the nature of palliative care may hinder assessment, management and evaluation of care and may contribute to the fear associated with living with breathlessness in the community.

Example: segmentation

In Bournemouth, there is a "Cardiac Breathlessness Clinic", aimed at diagnosing and following up heart failure patients in the community. It is led by the Heart Failure Team funded by Bournemouth PCT and staffed by a GPwSI working one session each week who provides the needed combination of generalist and specialist skills, and three part-time heart failure nurse specialists, clinically supported by the Cardiac Department at the Royal Bournemouth Hospital.

It works as a one-stop clinic for breathless patients in whom GPs feel that a cardiac cause might be responsible. The patient gets a holistic assessment, which includes not only clinical review, ECG, BNP and echocardiography, but also CXR and spirometry.

²³ C A Slader, H K Reddel, L M Spencer, E G Belousova, C L Armour, S Z Bosnic-Anticevich, F C K Thien, and C R Jenkins Double blind randomised controlled trial of two different breathing techniques in the management of asthma. *Thorax*, Aug 2006; 61: 651 - 656.

²⁴ Maher D, Hemming L.Palliative care for breathless patients in the community Br J Community Nurs. 2005 Sep;10(9):414-8. Review.

By the end of the assessment the service tries to establish a diagnosis and then faxes its findings, together with an action plan, to the primary care team within a couple of days. A proportion of patients need further cardiac investigation, which the team arranges directly; those with heart failure are also followed up by a specialist heart failure nurse to help with education, monitoring and medication.

d. Simplification (of pathway by reducing handoffs. Although might also include changing frequency of follow-up and review)

Pathway mapping work can also identify where patients are passed from one practitioner to another, with no added value for the patient. Redesign work then centres on reducing such "hand-offs", often by rethinking job roles. Skills for Health competences can help here. This change is likely to need to be supported by training. If there are any changes, the principle remains that the patient should know who is in charge of their care; and that the system knows who is accountable.

There is guidance for the frequency of review for asthma and COPD. QOF requires review every 15 months as a minimum. However it does not encourage more frquent review because it is a tick box process and does not capture the status of a patient's condition that is related to the status of their condition, it is simply a tick box so does not encourage more frequent review NICE COPD guidelines recommend increased frequency according to severity. The National Service Framework for COPD is also likely to recommend increased frequency. The important point is that it should be sufficiently flexible to suit the patient's needs at that time and sufficiently spaced so that the review captures changes in a timely way. Therefore a monitoring strategy would be helpful, which may well be self-monitoring or involve telemonitoring of vital functions (pulse rate, pulse oxygenation, blood pressure, core body temperature, ambient temperature etc.) that signal when early intervention may be appropriate. Investment into research in these areas is urgently needed.

Training

It is vital that if respiratory care is moved nearer to home that the workforce in properly trained using accredited teachers and courses.

8. Summary

- The NHS Institute's work on Care Outside Hospital identifies four approaches to achieving a shift: integration, substitution, segmentation and simplification. This paper uses these approaches, giving respiratory examples, acknowledging that in practice, these four approaches are often combined.
- Transforming outpatient care may be regarded as a "quick win". However, done in isolation from reviewing the whole pathway there is the potential to destabilise or distort care provision. Many of the examples illustrate how clinics are just one element of bigger improvements.
- The objective should be to provide patients with the right care at the right time, reliably, by the professional(s) most competent to provide their care.
- This would usefully involve a better match between primary care providing routine care, and specialists providing specialist expertise and insight.
- It would also make the most of primary care generalists' skills in providing much needed co-ordination of care for patients with physical and psychological co-morbidities.
- It should be remembered that the most important step in a pathway is to ensure the person has the correct diagnosis and so is put on the right pathway; therefore time and effort should be spent developing and making available the right assessment and diagnostic services, particularly for patients with co-morbidities.
- There should therefore be a distinction between the service required for accurate and early diagnosis, and that required for follow-up care.
- There are many opportunities to provide patient-centred care, which is closer to patients' homes for people with asthma and COPD.
- Decisions about location and level of specialism should be kept separate: a consultant can work in a community setting.
- The shift should be driven by an ambition to improve the personalisation of care, and to deliver it closer to home, not by a drive for savings.

- The key issue for many patients is about more flexible access, timing and mode of consultation with a healthcare professional of their choice. Currently primary care can normally offer more flexibility than secondary care and enables patients to choose what suits them at that point in their lives.
- Planning requires local stakeholder input. It should consider what has worked before (although recognising that there may be little data available about this, such as the impact on asthma care of the shift to primary care), local audits of referrals and what patients want.
- Successful service redesign needs the co-operation of clinicians, managers and patients across service boundaries.
- Commissioners must assess the competence of the local workforce to deliver any shift and have a clear set
 of indicators to judge its effectiveness. Local clinicians, particularly local specialists, have a responsibility to
 advise on this to support the development of skills across primary care, and to cooperate with evaluation. Commissioners should consider the opportunity for some specialists to actively educate and develop the local
 workforce. IMPRESS has proposed some standards of competence for COPD:
 www.impressresp.com/Commissioning/ProposedstandardsforcommissioningCOPDService/tabid/73/Default.aspx
- The health community has a responsibility to engage patients in any discussion about changes and to ensure they are reassured that the purpose of the change is to improve their experience of care.
- In the absence of national guidance on coding and payment, commissioners will need to make local agreements with their NHS providers about innovative approaches such as telephone consultations.
- There is limited evidence to date about the use of telemedicine but telephone and IT solutions are an increasing part of life and are therefore are becoming an expectation of service users. In this rapidly moving area, commissioners need to build flexibility into their plans and focus on outcomes not processes.
- It is important to understand the baseline for activity using routinely available data. If campaigns to identify those with COPD who are not yet diagnosed are successful, it is likely that this will require an increased level of intervention such as smoking cessation, and prescribing costs and care.
- The lack of national diagnostic coding of out-patient activity means that baseline data on which respiratory
 patients are currently receiving out-patient respiratory care is missing and makes planning new services more
 difficult.
- Models of care are changing all the time, and therefore commissioners should work with local clinicians and managers to develop a system that suit suits the local situation. In addition, IMPRESS will update this, and its other guides, as the evidence emerges.

Siân Williams 1 August 2008

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