

data will be linked across the three audit work streams and will be analysed centrally. Reports with benchmarking against the national average will be provided for all participating practices, with higher level reports for commissioners and other organisations at a regional and national level. The practice reports will offer support for standardised coding of records and service improvement. Changes will be measured in repeat audit cycles.

Whilst the collection of this database in England and Wales is itself a massive undertaking, the learning from Finland⁵ is that this is merely the beginning of a 5-year quality improvement programme. Within secondary care a peer review initiative is one option to drive improvements in care. For pulmonary rehabilitation programmes, an accreditation process is proposed which could drive up standards and assist commissioning of rehabilitation. One of the underlying principles of all such national audits is the open publication of data. This may be used to help patients and commissioners to understand the quality of services available.

The Swedish⁶ and Finnish⁵ National studies have shown what can be accomplished if a national effort is made to collect good quality data and to use those data to support clinicians in improving the quality of care delivered to COPD patients. We now plan to collect a much bigger dataset in England and Wales and use this to drive a multi-faceted quality improvement programme on the care of our COPD patients. This is an opportunity for clinicians to deliver a long overdue UK national health improvement programme on a grand scale for a previously neglected group of people.

Conflicts of interest The authors declare that they have no conflicts of interest in relation to this article.

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References

1. Chavannes N, Stallberg B, Lisspers K, et al. UNLOCK: Uncovering and noting long-term outcomes in COPD to enhance knowledge. *Prim Care Respir J* 2010;**19**(4): 408. <http://dx.doi.org/10.4104/pcrj.2010.00084>
2. Price D, Hillyer EV, van der Molen T. Efficacy versus effectiveness trials: informing guidelines for asthma management. *Current Opinion in Allergy and Clinical Immunology* 2013;**13**(1):50-7. <http://dx.doi.org/10.1097/ACI.0b013e32835ad059>
3. Suissa S, Patenaude V, Lapi F, Ernst P. Inhaled corticosteroids in COPD and the risk of serious pneumonia. *Thorax* 2013;**68**(11):1029-36. <http://dx.doi.org/10.1136/thoraxjnl-2012-202872>
4. Observatory ERPH. NHS Atlas of Variation in Healthcare for People with Respiratory Disease 2012.
5. Kinnula VL, Vasankari T, Kontula E, Sovijarvi A, Saynajakangas O, Pietinalho A. The 10-year COPD Programme in Finland: effects on quality of diagnosis, smoking, prevalence, hospital admissions and mortality. *Prim Care Respir J* 2011;**20**(2):178-83. <http://dx.doi.org/10.4104/pcrj.2011.00024>
6. Ställberg B, Janson C, Johansson G, Larsson K, Stratelis G, Telg G, Lisspers KH. Management, morbidity and mortality of COPD during an 11-year period: an observational retrospective epidemiological register study in Sweden (PATHOS). *Prim Care Respir J* 2014;**23**(1):38-45. <http://dx.doi.org/10.4104/pcrj.2013.00106>
7. Janson C, Larsson K, Lisspers KH, et al. Pneumonia and pneumonia related mortality in patients with COPD treated with fixed combinations of inhaled corticosteroid and long acting β_2 agonist: observational matched cohort study (PATHOS). *BMJ* 2013;**346**:f3306. <http://dx.doi.org/10.1136/bmj.f3306>
8. Sundh J, Janson C, Lisspers K, Stallberg B, Montgomery S. The Dyspnoea, Obstruction, Smoking, Exacerbation (DOSE) index is predictive of mortality in COPD. *Prim Care Respir J* 2012;**21**(3):295-301. <http://dx.doi.org/10.4104/pcrj.2012.00054>
9. George PM, Stone RA, Buckingham RJ, Pursey NA, Lowe D, Roberts CM. Changes in NHS organization of care and management of hospital admissions with COPD exacerbations between the national COPD audits of 2003 and 2008. *QJM* 2011;**104**(10):859-66. <http://dx.doi.org/10.1093/qjmed/hcr083>
10. Department of Health. An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England. London, 2011.
11. The National Institute for Health and Clinical Excellence. Chronic Obstructive Pulmonary Disease Quality standard advice to the Secretary of State for Health. London, 2011.

On Goldilocks, care coordination, and palliative care: making it 'just right'

See linked article by Epiphaniou *et al.* on pg 46

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Hospice/palliative care is not just end-of-life care, it is specialised medical care for patients with serious illness.¹ Although definitions of "serious illness" may vary, it is clear that far more patients could benefit from hospice/palliative care than we can actually serve, given the existing workforce challenges and the lack of clarity in how to pay for specialist palliative care throughout the world. The needs of patients and caregivers are similar regardless of the underlying life limiting illness.²⁻⁴

Appropriate timing of referrals is key, but this timing must be clearly defined for each disease group, with differences to be expected between cancer and COPD.⁵ Not every patient needs to see a palliative care specialist, and the timing matters greatly when resources are limited.⁶ Thus, as palliative care continues to move further upstream in a patient's journey, these limitations necessitate that we be better able to match the right type of care with the right patient at the right time. Models of "care coordination" offer one potentially promising strategy for addressing this problem.

In this issue of the *PCRJ*, Epiphaniou and colleagues⁷ report the results of a longitudinal qualitative study of patients' experiences with end-of-life care coordination in the UK. These results highlight several important truths about the current state of care coordination. First, patients with COPD had little access to care coordinators (or "keyworkers" as they are called here). These patients are at risk for increasingly frequent re-hospitalisations as the disease progresses, and avoiding hospital is a crucial way of improving care and decreasing healthcare costs. Given the very long illness trajectory for people with COPD,⁸ they may seem less in need of care coordination, and are often left without easy access to close follow-up care after hospital discharge. Patients with COPD in this study expressed a sense of feeling left out on their own without much support.

Patients with lung cancer, on the other hand, routinely had access to a care coordinator.⁷ Among those who did, nearly all felt it was valuable. These findings highlight the remarkably positive role care coordinators can play in the life of a patient with serious illness. Patients frequently described how useful the coordinator was in responding to their needs by matching them with various services, and helping them contact their physicians. The complex care needed for those with advanced illness can be very overwhelming and patients may need a "disease shepherd" to help show them the way.

These key concepts of care coordination are central to the care that is provided by hospice/palliative care services around the world. Such care might be expected to result in fewer emergency department visits or hospital stays for patients with serious, progressive illnesses. Interestingly, despite its intuitive appeal, care coordination actually does not always result in improved outcomes. In fact, published studies have been somewhat mixed. For example, a similar concept was tested in the US cancer setting, using "nurse navigators."⁹ In a randomised controlled trial, this intervention yielded improvements in psychosocial care, care coordination, and patient information, but actually did not improve quality of life. It also did not reduce costs, except in a subset with lung cancer. Similarly, in a large randomised trial of a tele-health intervention for patients with COPD,¹⁰ a daily symptom and medication monitoring approach was not effective in reducing re-hospitalisations or improving quality of life. Though slightly different from care coordinators, this finding puts forward the challenge of how best to apply findings from the study by Epiphaniou *et al.*⁷ to populations of people with COPD.

Another noteworthy study of care coordination is the "Palliative Care Trial."^{11,12} Here, the implementation of a single patient-focused case conference, coordinated by a palliative care nurse in concert with the general practitioner (GP), was shown to reduce hospitalisations by 26% and to provide better maintenance of performance status. The

nurse and GP assessed the patient's needs and translated these to the multidisciplinary case conference, bringing the patient's voice to the plan of care. This approach embodies the "disease shepherd" model by helping match the right support services to the right patient in a timely way. Referrals and use of scarce resources are thus based on need, rather than diagnosis or prognosis. As so conceived, a care coordinator may be the very steward that we need to judiciously expand palliative care services to those patients who are particularly likely to need and/or benefit from accessing them.

In heart failure, a nurse-led intervention comprising comprehensive education, social-service consultation, and intensive follow-up reduced 90-day heart failure readmission by 56.2%, improved quality of life, and reduced the cost of care.¹³ A meta-analysis of published trials of post-discharge support strategies further supports these findings.¹⁴ In contrast, enhanced access to primary care for heart failure patients did not improve their self-reported health status and was actually associated with more frequent hospitalisation.¹⁵ Reconciling these findings will be important in moving science forward in this area.

In the end, what do these somewhat contradictory results mean for hospice/palliative care, and for clinicians who face the difficult decision about timing a referral or who are trying to adopt a model of care coordination? Wherein lies the "transition point" – the "Goldilocks point" – where it is exactly the right time to mobilise specialist hospice/palliative care services for the patient sub-group who will derive the most benefit? Whilst we do not pretend to have all the answers, we do propose a path forward in terms of further research. More work is needed to explore the role of functional limitations, the onset of troublesome symptoms, or both, as a potentially useful threshold to trigger further care coordination. The onset of functional decline often portends a poor prognosis, especially in cancer settings,¹⁶ and symptoms often signal an impending need for emergency or inpatient services. Symptoms can now be monitored in the home using emerging technological applications,¹⁷ and once decline is noted, care coordination could be mobilised to assess the potential need for additional services. More active use of mobile health technology solutions is likely to play an important role in solving this puzzle, helping us match the right care to the right patient at the right time. Care coordinators will not fix all of palliative care's service planning problems, but are a key part of the solution if appropriately applied. Regardless, further study is needed not only on their impact on patients, but also on patients' caregivers.

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References

1. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. *N Engl J Med* 2013;**368**(13):1173-5. <http://dx.doi.org/10.1056/NEJMp1215620>
2. Luddington L, Cox S, Higginson I, Livesley B. The need for palliative care for patients with non-cancer diseases: a review of the evidence. *Int J Palliat Nurs* 2001;**7**(5):221-6.
3. Currow DC, Ward A, Clark K, Burns CM, Abernethy AP. Caregivers for people with end-stage lung disease: characteristics and unmet needs in the whole population. *Int J Chron Obstruct Pulmon Dis* 2008;**3**(4):753-62.
4. Girgis A, Abernethy AP, Currow DC. Caring at the end of life: do cancer caregivers differ from other caregivers? *BMJ Support Palliat Care* 2014; Published Online First 22 January 2014. <http://dx.doi.org/10.1136/bmjspcare-2013-000495>
5. Curtis JR. Palliative and end-of-life care for patients with severe COPD. *Eur Respir J* 2008;**32**(3):796-803. <http://dx.doi.org/10.1183/09031936.00126107>
6. Currow DC, Abernethy AP, Fazekas BS. Specialist palliative care needs of whole populations: a feasibility study using a novel approach. *Palliat Med* 2004;**18**(3):239-47. <http://dx.doi.org/10.1191/0269216304pm873oa>
7. Epiphaniou C, Shipman C, Harding R, Mason B, Murray SAA, Higginson IJ, Daveson BA. Coordination of end-of-life care for patients with lung cancer and those with advanced COPD: are there transferable lessons? A longitudinal qualitative study. *Prim Care Respir J* 2014;**23**(1):46-51. <http://dx.doi.org/10.4104/pcrj.2014.00004>
8. Currow DC, Plummer JL, Crockett A, Abernethy AP. A community population survey of prevalence and severity of dyspnea in adults. *J Pain Symptom Manage* 2009;**38**(4):533-45. <http://dx.doi.org/10.1016/j.jpainsymman.2009.01.006>
9. Wagner EH, Ludman EJ, Aiello Bowles EJ, et al. Nurse navigators in early cancer care: a randomized, controlled trial. *J Clin Oncol* 2014;**32**(1):12-18. <http://dx.doi.org/10.1200/JCO.2013.51.7359>
10. Pinnock H, Hanley J, McCloughan L, et al. Effectiveness of telemonitoring integrated into existing clinical services on hospital admission for exacerbation of chronic obstructive pulmonary disease: researcher blind, multicentre, randomised controlled trial. *BMJ* 2013;**347**:f6070. <http://dx.doi.org/10.1136/bmj.f6070>
11. Abernethy AP, Currow DC, Hunt R, et al. A pragmatic 2 x 2 x 2 factorial cluster randomized controlled trial of educational outreach visiting and case conferencing in palliative care-methodology of the Palliative Care Trial [ISRCTN 81117481]. *Contemp Clin Trials* 2006;**27**(1):83-100. <http://dx.doi.org/10.1016/j.cct.2005.09.006>
12. Abernethy AP, Currow DC, Shelby-James T, et al. Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: results from the "palliative care trial" [ISRCTN 81117481]. *J Pain Symptom Manage* 2013;**45**(3):488-505. <http://dx.doi.org/10.1016/j.jpainsymman.2012.02.024>
13. Rich MW, Beckham V, Wittenberg C, Leven CL, Freedland KE, Carney RM. A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure. *N Engl J Med* 1995;**333**(18):1190-5. <http://dx.doi.org/10.1056/NEJM199511023331806>
14. Phillips CO, Wright SM, Kern DE, Singa RM, Shepperd S, Rubin HR. Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure: a meta-analysis. *JAMA* 2004;**291**(11):1358-67. <http://dx.doi.org/10.1001/jama.291.11.1358>
15. Oddone EZ, Weinberger M, Giobbie-Hurder A, Landsman P, Henderson W. Enhanced access to primary care for patients with congestive heart failure. Veterans Affairs Cooperative Study Group on Primary Care and Hospital Readmission. *Eff Clin Pract* 1999;**2**(5):201-09.
16. Suh SY, Leblanc TW, Shelby RA, Samsa GP, Abernethy AP. Longitudinal patient-reported performance status assessment in the cancer clinic is feasible and prognostic. *J Oncol Pract* 2011;**7**(6):374-81. <http://dx.doi.org/10.1200/JOP.2011.000434>
17. Kumar S, Nilsen WJ, Abernethy A, et al. Mobile health technology evaluation: the mHealth evidence workshop. *Am J Prev Med* 2013;**45**(2):228-36. <http://dx.doi.org/10.1016/j.amepre.2013.03.017>

Predicting the outcome of early childhood wheeze: mission impossible

See linked article by Cano-Garcinuño *et al.* on pg 60

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Every general practitioner (GP) knows that many young children wheeze during upper respiratory tract infections, and that most of these children do not become asthmatic later during childhood. Data from population-based studies show that one in three children will have at least one episode of wheezing during

the first three years of life.¹ Two-thirds of these preschool wheezers outgrow their symptoms by the age of six, and the remaining third develop asthma.^{1,2} Wouldn't it be great if we could predict which preschool wheezer will become asthmatic and which will not? Such knowledge would not only be useful for counselling parents, but could also be used to target therapy. Given our ongoing concerns over the safety of inhaled corticosteroids, particularly in young children,³ we prefer to avoid treating transient preschool wheezers unnecessarily with daily controller treatment for asthma.

Until recently, the knowledge about which factors were associated with the persistence or remittance of preschool wheeze came from general population birth cohort studies.¹ The asthma predictive scores based on these studies show a statistically significant association with asthma and wheeze at age six years, but their value for predicting the outcome of preschool wheeze in individual cases is poor.⁴ Since not all young children with wheeze are brought to their GP, the applicability of these asthma predictive scores in primary care is unclear. In addition, because parents use the word "wheeze" to describe a range