

# National cohort data from Sweden to the National COPD audit in England and Wales: grand designs for quality improvement

See linked article by Stallberg *et al.* on pg 38

\*Rupert Jones<sup>1</sup>, Michael Roberts<sup>2</sup>

<sup>1</sup> Clinical Research Fellow, Plymouth University Peninsula Schools of Medicine and Dentistry, Plymouth, UK; General Practitioner, Armada Surgery, Plymouth, UK

<sup>2</sup> Dean, Barts and The London School of Medicine and Dentistry, Queen Mary University of London, London, UK; Head, UK National COPD Audit Programme

\*Correspondence: Dr Rupert Jones, Clinical Research Fellow, Plymouth University Peninsula Schools of Medicine and Dentistry, 1 Davy Road (N21), Plymouth, PL6 8BX, UK  
Tel & Fax: +44 01752 764259  
E-mail: rupert.jones@plymouth.ac.uk

The computerisation of clinical patient records in primary care provides an opportunity to collect health care data at national and international level. There is a dawning awareness of the enormous potential of such data, both as a research tool and as a means to improve the quality of health care provision. For commissioners and service planners there is a golden opportunity to lead the way in the constructive use of data to the benefit of both clinicians and patients.

Such an example is the exploitation of routinely collected data from primary care for research. From the august origins of the General Practice Research Database, a plethora of datasets are now available with data on demographics, diagnoses, tests, treatments and outcomes. Researchers can now link general practice data with data from other sources such as hospital statistics and national registers of cancer and death, thus providing huge potential for the study of disease prevalence, interaction of co-morbidities, and impacts on outcomes.

Gathering data from multiple primary care sources remains a challenge, however, and this is being addressed in various ways. The Scandinavian countries have developed large datasets using disease registries, notably for COPD, which provide access to massive longitudinal data. International researchers such as those involved in the UNLOCK<sup>1</sup> study and the Respiratory Effectiveness Group, are combining large datasets to answer specific questions. Ground rules on methodology and use in guidelines are being set.<sup>2</sup> From this there has emerged a series of projects – e.g. the evaluation of the properties of prognostic indices.<sup>3</sup>

A second use of large datasets is for clinical audit, which involves either collection of data and/or analysis of existing data sources to bring about quality improvements in health care. In this way, variation in health care between areas<sup>4</sup> and individual providers can be identified, and by benchmarking against standards remedial action can be targeted at poor performers.

Finland has been an exemplar of true audit, with a coordinated national COPD multidisciplinary education and health improvement intervention informed by clinical data.<sup>5</sup> A series of national data collections carried out over a 10-year period demonstrated sustained quality improvement and a reduction in hospital admissions.

In this issue of the *PCRJ*, Ställberg *et al.* report the findings from a Swedish national register study with a representative sample of data collected prospectively for 11 years on 21,000 patients with COPD from 76 primary care centres.<sup>6</sup> Primary care data was linked to death registers yielding influential studies on disease management and prognosis.<sup>7,8</sup> Over time this audit has demonstrated clear improvements in the quality of care received by these COPD patients in Sweden.

A strength of the Ställberg study was the use of well recorded clinical computerised notes with searchable codes. However, not all items were routinely recorded – for example, only one-third had smoking data and only 29% had data on spirometry. Recorded smoking data was likely to be of high quality, but the data may be of lesser quality for items such as spirometry, which is affected by the expertise of the operator. Exacerbation recording is crucial, but often poorly documented; in this study the authors used a sensible approach, using a composite method to estimate exacerbation frequency – admissions or oral steroid or oral antibiotics prescribed “because of respiratory symptoms”.

Improving data recording and data quality are vital audit aims. The Finnish experience is that data collection used to define education interventions coupled with feedback and support when delivered as a holistic programme does make a difference to the quality of care received by COPD patients.

Within the UK, audit has been central to the use of datasets and quality improvement, but there have been disappointing results for COPD secondary care.<sup>9</sup> A new national audit of England and Wales is being launched this year, which will collect data from across primary and secondary care. What learning from the Swedish<sup>6</sup> and Finnish<sup>5</sup> experience can be used to improve the impact of this initiative?

The England and Wales COPD audit is an ambitious 5-year programme led by a consortium of professional, patient and carer organisations. There are three main work streams – Primary Care, Hospital Care, and Pulmonary Rehabilitation – together with a 12-month feasibility study of the collection of Patient Reported Experience Measures across all three work streams. It is hoped that data from around 750,000 people with COPD will be collected in 2014. The primary care audit measures include key processes of care and patient outcomes. Data will be blueprinted against national guidance.<sup>10,11</sup> Electronic codes will be used to identify relevant data within General Practice clinical systems from which process items and outcomes will be extracted by the Health and Social Care Information Centre. These data will in turn be linked to other national data sources using UK National Health Service (NHS) patient numbers as a unique identifier, then pseudo-anonymised for analytical purposes. Patient

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 Finland<sup>5</sup> 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 Swedish<sup>6</sup> and Finnish<sup>5</sup> 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.

Commissioned article; not externally peer reviewed; accepted 4th February 2014; online 19th February 2014

© 2014 Primary Care Respiratory Society UK. All rights reserved  
<http://dx.doi.org/10.4104/pcrj.2014.00013>  
*Prim Care Respir J* 2014; 23(1): 7-8

## 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  $\beta_2$  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

Thomas W LeBlanc<sup>1,2</sup>, David C Currow<sup>3</sup>,  
 \*Amy P Abernethy<sup>2,4</sup>

- 1 Division of Hematologic Malignancies and Cellular Therapy, Department of Medicine, Duke University School of Medicine, Durham, NC USA
- 2 Center for Learning Health Care, Duke Clinical Research Institute, Durham, NC USA
- 3 Discipline, Palliative and Supportive Services, Flinders University, Adelaide, Australia
- 4 Division of Medical Oncology, Department of Medicine, Duke University School of Medicine, Durham, NC USA

\*Correspondence: Dr Amy Abernethy, Box 3436, Duke University Medical Center, Durham, NC 27710  
 Tel: 919 668 0647 Fax: 919-681-7985  
 E-mail: amy.abernethy@duke.edu

Hospice/palliative care is not just end-of-life care, it is specialised medical care for patients with serious illness.<sup>1</sup> 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.<sup>2-4</sup>