Lung cancer

**BMJ** Open Respiratory Research

## Integrated care for resected early stage lung cancer: innovations and exploring patient needs

Jan Ho,<sup>1</sup> Annette McWilliams,<sup>2,3</sup> Jon Emery,<sup>4</sup> Christobel Saunders,<sup>3,5</sup> Christopher Reid,<sup>6</sup> Suzanne Robinson,<sup>6</sup> Fraser Brims<sup>1,7</sup>

To cite: Ho J, McWilliams A, Emery J, et al. Integrated care for resected early stage lung cancer: innovations and exploring patient needs. BMJ Open Resp Res 2017:4:e000175. doi:10.1136/ bmjresp-2016-000175

Received 4 December 2016 Revised 3 May 2017



<sup>1</sup>Department of Respiratory Medicine, Sir Charles Gairdner Hospital, Nedlands, Western Australia, Australia <sup>2</sup>Department of Respiratory Medicine, Fiona Stanley Hospital, Murdoch, Western Australia, Australia <sup>3</sup>School of Medicine and Pharmacology, University of Western Australia, Perth, Western Australia, Australia <sup>4</sup>General Practice and Primary Health Care Academic Centre, The University of Melbourne, Carlton, Victoria, Australia <sup>5</sup>Department of Surgery, Fiona Stanley Hospital, Perth, Western Australia, Australia <sup>6</sup>School of Public Health, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia <sup>7</sup>Curtin Medical School, Faculty of Health Sciences, Curtin University, Perth, Western Australia, Australia

### Correspondence to

BMJ

Professor Fraser Brims; fraser.brims@curtin.edu.au

#### **ABSTRACT**

There is no consensus as to the duration and nature of follow-up following surgical resection with curative intent of lung cancer. The integration of cancer follow-up into primary care is likely to be a key future area for quality and cost-effective cancer care. Evidence from other solid cancer types demonstrates that such follow-up has no adverse outcomes, similar health-related quality of life, high patient satisfaction rates at a lower cost to the healthcare system. Core elements for successful models of shared cancer care are required: clear roles and responsibilities, timely effective communication, guidance on follow-up protocols and common treatments and rapid routes to (re)access specialist care. There is thus a need for improved communication between hospital specialists and primary care. Unmet needs for patients with early stage lung cancer are likely to include psychological symptoms and carer stress; the importance of smoking cessation may frequently be overlooked or underappreciated in the current hospital-based follow-up system. There is therefore a need for quality randomised controlled trials of patients with resected early stage lung cancer to establish optimal protocols for primary carebased follow-up and to more adequately address patients' and carers' unmet psychosocial needs, including the crucial role of smoking cessation.

#### INTRODUCTION

Lung cancer is the most commonly diagnosed cancer worldwide, and surgery offers the best chance of cure or long-term survival. There are variable early stage lung cancer surgical rates across developed countries of between 5% and 21%.<sup>2</sup> Patients with resected early stage lung cancer have recurrence rates of between 30% and 75%,3 and it is likely that with increasing interest in and adoption of screening for lung cancer,4 rates of those having surgery for early stage disease may increase. In addition, patients with a previous lung cancer are at high risk of developing metachronous lung cancers at a rate of 1%–5% per annum.

There is no consensus as to the duration and nature of follow-up following curative surgical resection of lung cancer with the

most recent American guidelines citing the evidence base as 'weak, low quality'. Typically, after postoperative follow-up, current practice involves CT of the chest at 6 months and then annually up to 5 years after resection. The American guidelines recommend every 6 months for 2 years, 6 although there is a wide variation in practice in across countries with similar healthcare systems. This follow-up is normally hospital based, with respiratory specialists or thoracic surgeons. After lobectomy, local recurrence is most common in the first 2 years with the risk of recurrence nearly twofold higher (HR 1.86; 95% CI 1.01 to 3.41) in persistent smokers.

Cost-effective healthcare relies on the provision of appropriate care in the right time at the right place; countries with a strong primary care component have been demonstrated to be more cost-effective than those that are over-reliant on hospital-led services.8 As cancer survival rates increase, the focus on managing patient flow back into primary care is a key area for future-effective and cost-effective cancer care.9 It is recognised that follow-up of patients undergoing palliative surgical interventions is very different; these patients are likely to benefit from regular secondary care contact. 10 This article will concentrate on follow-up after surgery with curative intent for non-small cell lung cancer (NSCLC).

## The role of primary care in follow-up of patients

There is increasing acceptance of the role of primary care in the follow-up of cancer survivors, 11-14 and in turn this is seen as increasingly critical for the long-term sustainability for healthcare systems in many developed countries. 15 In many developed countries, there is an increasing financial demand on secondary and tertiary care services. There is thus a need to better define which clinical services







require specialist oversight and which conditions could, perhaps with appropriate guidance and oversight, <sup>16</sup> <sup>17</sup> be acceptably managed within primary care.

Evidence from randomised clinical studies in bowel and breast cancer follow-up suggests that integrated follow-up in primary care has no adverse outcomes, similar health-related quality of life and high patient satisfaction rates. <sup>18</sup> The results of an Australian randomised control trial examining integrated care with hospitals and general practitioners (GPs) for patients with prostate cancer also demonstrated that this was a safe and acceptable model of care at lower cost to the healthcare system. <sup>20</sup> GPs feel confident and enabled to contribute to long-term cancer care <sup>21</sup> and cancer survivors are satisfied with care delivery in primary care. <sup>22</sup>

There have been a number of studies examining follow-up of lung cancer in different settings. A retrospective cohort study in Japan reported the outcomes of postoperative patients with NSCLC dependent on follow-up with either thoracic surgeons or chest physicians. Survival in more advanced stage disease was better with the chest physician group; there was data to suggest that the use of regular CT chest scans may improve detection of recurrence (or new primary) to enable therapy with curative intent (regardless of doctor in charge of follow-up).

Another retrospective cohort study from Canada describes outcomes of postsurgical patients with NSCLC, comparing thoracic surgeon followed by other health professionals.<sup>24</sup> Despite hospital clinic follow-up, two-thirds of recurrences were detected by the patient's GP, with no overall survival differences. It was postulated that GP-based care might be associated with 75% cost savings from follow-up. A randomised controlled trial from the UK comparing nurse-led care with conventional approaches for advanced NSCLC reported improved satisfaction, earlier recognition of deterioration, better emotional functioning, fewer consultations and no difference in survival with nurse-led care.<sup>25</sup> Nurse-led care is reported to be acceptable to patients, carers, GPs and treating physicians. 26 Such non-specialist follow-up may therefore be acceptable as long as there are clear protocols including the ability to refer to specialists easily and access to appropriate radiology.<sup>26</sup>

The potential shift in the care for patient with cancer with greater GP involvement also raises concerns that GP workloads may be increased. There is additional concern that perhaps GPs will see very few of these cases in their practice and thus may not be adequately confident or have sufficient experience to safely follow-up these patients. The proposed solution in this situation would be the use of a protocol in conjunction with clinical acumen to guide follow-up. Evidence suggests that certain core elements for successful models of shared cancer care are required: clear roles and responsibilities for GPs, timely effective communication about care, guidance on follow-up protocols and management of common treatment side effects and rapid routes to access

specialist care. <sup>16</sup> <sup>17</sup> <sup>20</sup> Therefore, a more collaborative and integrated approach would allow GPs to participate more with the follow-up care of patients with cancer, perhaps with integration with virtual or remote monitoring clinics from secondary care.

In some countries, access to specialist care varies, notably, specialist visits in populations that have a lower income or education levels are lower. The inequity in specialist access favours the populations with higher income and education in Organisation for Economic Co-operation and Development countries. <sup>22 23 29 30</sup> Access to GPs, which is comparably better than access to specialists, would potentially improve this inequity and allow the same (or improved) standards of care.

#### **Unmet needs for patients with lung cancer**

As acknowledged in the National Institute for Health and Care Excellence lung cancer clinical guidelines, there are sparse data examining unmet needs for patients with early stage lung cancer. 10 Interviews with patients with lung cancer (with more advanced stage) have identified at least moderate levels of anxiety and depression.<sup>31</sup> A further study reported that hospital consultants were failing to recognise anxiety in many patients and largely overlooked the needs of informal carers (in whom it was reported had the greatest onus of care). 32 Key areas of unmet need may be most apparent during periods away from acute care.<sup>32</sup> Other in depth interviews with patients with lung cancer and carers identified feelings of isolation and identified a need for coordinated family-oriented care.<sup>33</sup> Patients identified a reliance on their hospital-based consultant and found it difficult to transition back to primary (or palliative) care. Variations in perceptions of care may be associated with a patients' educational level, with a higher level of education associated with more focus on the logistics of care, rather than the psychosocial aspects.<sup>34</sup>

There is a further unmet need to support smoking cessation in lung cancer survivors with a 5-year survival rate following resection for lung cancer of 77% in those able to quit and 33% in those unable to quit smoking. Between our two institutions, 33%–62% of newly diagnosed lung cancer cases between 2015 and 2016 were current smokers at the time of their diagnosis (unpublished data). Physicians and surgeons who treat lung cancer give limited smoking cessation advice and implementation of plans due to limited resources. Smoking cessation and support for other behaviour change are key roles of primary care with links to community-based resources to support patients to stop smoking and adopt a healthier lifestyle.

Therefore, the present system of hospital-based care may not be adequately identifying all the needs of a patient with lung cancer, in particular, psychosocial aspects. There is further need for improved communication between hospital specialists and GPs<sup>33</sup> <sup>36</sup> <sup>37</sup> and a more personalised explanation of treatment plan for



patients.<sup>38</sup> It is already accepted that primary care physicians are motivated and capable of providing follow-up to patients with cancer after their initial treatment, with good satisfaction among patients. Additionally, there is an identified economic need to decentralise care away from secondary and tertiary centres where possible.<sup>15</sup>

We contend that there is a need for quality randomised controlled trials of patients with resected early stage lung cancer to elucidate suitable patient populations for GP-led follow-up, development of protocols for optimal follow-up, more adequately address patients' and carers' unmet psychosocial needs and perform an economic evaluation of such an approach to guide future follow-up of these highrisk patients. There is further need for the development of a quality lung cancer registries (similar to the highly successful UK-based National Lung Cancer Audit database) that will not only lead to improved patient care but also may facilitate registry-based trials in the future. 40 41

#### **CONCLUSION**

Currently, there is inadequate data to inform the optimal care of patients who have had surgery for early stage lung cancer with curative intent. The current hospital-based system may not be addressing holistic patient-oriented care (including smoking cessation) adequately, together with the suboptimal use of secondary and tertiary hospital resources. High quality data and randomised studies are required to evaluate these key issues and improve care for these patients.

Correction notice This paper has been amended since it was published Online First. Owing to a scripting error, some of the publisher names in the references were replaced with 'BMJ Publishing Group'. This only affected the full text version, not the PDF. We have since corrected these errors and the correct publishers have been inserted into the references.

**Contributors** JH drafted the initial manuscript, reviewed articles and submitted the manuscript for publishing. AMW, CS, CR, JE and SR provided opinions and revisions for the manuscript. FB drafted the final manuscript and did the corrections.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Not applicable.

Open Access This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: http://creativecommons.org/licenses/by/4.0/

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2017. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

#### REFERENCES

- Torre LA, Bray F, Siegel RL, et al. Global cancer statistics, 2012. CA Cancer J Clin 2015;65:87–108.
- Verdecchia A, Francisci S, Brenner H, et al. Recent cancer survival in Europe: a 2000-02 period analysis of EUROCARE-4 data. Lancet Oncol 2007:8:784-96.
- Sugimura H, Nichols FC, Yang P, et al. Survival after recurrent nonsmall-cell lung cancer after complete pulmonary resection. Ann Thorac Surg 2007;83:409–18.
- Brims F, McWilliams A, Fong K. Lung cancer screening in Australia: progress or procrastination? Med J Aust 2016;204:4–5.

- Lou F, Huang J, Sima CS, et al. Patterns of recurrence and second primary lung cancer in early-stage lung cancer survivors followed with routine computed tomography surveillance. J Thorac Cardiovasc Surg 2013;145:75–82.
- Colt HG, Murgu SD, Korst RJ, et al. American College of chest Physicians evidence-based clinical practice guidelines. Follow-up and surveillance of the patient with lung cancer after curativeintent therapy: Diagnosis and management of lung cancer. Chest 2013;143:e437S.
- Parsons A, Daley A, Begh R, et al. Influence of smoking cessation after diagnosis of early stage lung cancer on prognosis: systematic review of observational studies with meta-analysis. BMJ 2010;340:b5569.
- Macinko J, Starfield B, Shi L. The contribution of primary care systems to health outcomes within Organization for Economic Cooperation and Development (OECD) countries, 1970-1998. *Health* Serv Res 2003;38:831–65.
- 9. Emery J, Trevena L, Mazza D, et al. The role of primary and communitybased healthcare professionals in early detection and follow-up in cancer care—a rapid review of best practice models: an evidence check rapid review brokered by the Sax Institute. Sydney: Cancer Institute, NSW, 2012.
- National Institute for Health and Care Excellence. The diagnosis and treatment of lung cancer (update) full guideline CG 121. Cardiff: National Institute for Health and Care Excellence, 2011.
- Emery J, Doorey J, Jefford M, et al. Protocol for the ProCare Trial: a phase II randomised controlled trial of shared care for follow-up of men with prostate cancer. BMJ Open 2014;4:e004972.
- Pascoe SW, Neal RD, Allgar VL, et al. Psychosocial care for cancer patients in primary care? Recognition of opportunities for cancer care. Fam Pract 2004;21:437–42.
- Rubin G, Berendsen A, Crawford SM, et al. The expanding role of primary care in cancer control. Lancet Oncol 2015;16:1231–72.
- Emery JD, Shaw K, Williams B, et al. The role of primary care in early detection and follow-up of cancer. Nat Rev Clin Oncol 2014;11:38–48.
- Richards M, Corner J, Maher J. The National Cancer survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. *Br J Cancer* 2011;105:S1–S4.
- Lizama N, Johnson CE, Ghosh M, et al. Keeping primary care "in the loop": General practitioners want better communication with specialists and hospitals when caring for people diagnosed with cancer. Asia Pac J Clin Oncol 2015;11:152–9.
- Johnson CE, Lizama N, Garg N, et al. Australian general practitioners' preferences for managing the care of people diagnosed with cancer. Asia Pac J Clin Oncol 2014;10:e90–e98.
- Grunfeld E, Levine MN, Julian JA, et al. Randomized trial of longterm follow-up for early-stage breast cancer: a comparison of family physician versus specialist care. J Clin Oncol 2006;24:848–55.
- Wattchow DA, Weller DP, Esterman A, et al. General practice vs surgical-based follow-up for patients with colon cancer: randomised controlled trial. Br J Cancer 2006;94:1116–21.
- Emery JD, Jefford M, King M, et al. ProCare Trial: a phase II randomized controlled trial of shared care for follow-up of men with prostate cancer. BJU Int 2017;119.
- Fidjeland HL, Brekke M, Vistad I. General practitioners' attitudes toward follow-up after cancer treatment: a cross-sectional questionnaire study. Scand J Prim Health Care 2015;33:223–32.
- Nyarko E, Metz JM, Nguyen GT, et al. Cancer survivors' perspectives on delivery of survivorship care by primary care physicians: an internet-based survey. BMC Fam Pract 2015;16:143.
- Nakamura R, Kurishima K, Kobayashi N, et al. Postoperative follow-up for patients with non-small cell lung cancer. Onkologie 2010;33:8–18.
- Gilbert S, Reid KR, Lam MY, et al. Who should follow up lung cancer patients after operation? Ann Thorac Surg 2000;69:1696–700.
- Moore S, Corner J, Haviland J, et al. Nurse led follow up and conventional medical follow up in management of patients with lung cancer: randomised trial. BMJ 2002;325:1145.
- Cox K, Wilson E, Heath L, et al. Preferences for follow-up after treatment for lung cancer: assessing the nurse-led option. Cancer Nurs 2006;29:176–87.
- Dawes AJ, Hemmelgarn M, Nguyen DK, et al. Are primary care providers prepared to care for survivors of breast cancer in the safety net? Cancer 2015;121:1249–56.
- Schmidt-Hansen M, Baldwin DR, Hasler E. What is the most effective follow-up model for lung cancer patients? A systematic review. J Thorac Oncol 2012;7:821–4.
- van Doorslaer E, Masseria C, Koolman X, et al. Inequalities in access to medical care by income in developed countries. CMAJ 2006;174:177–83.



- Glazier RH, Agha MM, Moineddin R, et al. Universal health insurance and equity in primary care and specialist office visits: a populationbased study. Ann Fam Med 2009;7:396–405.
- Hotta K, Kiura K, Takigawa N, et al. Desire for information and involvement in treatment decisions: lung cancer patients' preferences and their physicians' perceptions: results from Okayama Lung Cancer Study Group Trial 0705. J Thorac Oncol 2010;5:1668–72.
- Krishnasamy M, Wilkie E, Haviland J. Lung cancer health care needs assessment: patients' and informal carers' responses to a national mail questionnaire survey. *Palliat Med* 2001;15:213–27.
  Krishnasamy M, Wells M, Wilkie E. Patients and carer experiences of
- Krishnasamy M, Wells M, Wilkie E. Patients and carer experiences of care provision after a diagnosis of lung cancer in Scotland. Support Care Cancer 2007;15:327–32.
- 34. Jacobs-Lawson JM, Schumacher MM, Hughes T, et al. The relationship between lung cancer patients' educational level and evaluation of their treatment information needs. *J Cancer Educ* 2009;24:346–50.
- 35. Warren GW, Dibaj S, Hutson A, et al. Identifying targeted strategies to improve smoking cessation support for cancer patients. *J Thorac Oncol* 2015;10:1532–7.

- McCarthy M, Datta P, Sherlaw-Johnson C. Organizational determinants of patients' experiences of care for breast, lung and colorectal cancers. *Eur J Cancer Care* 2009;18:287–94.
- Hodgkinson K, Butow P, Hobbs KM, et al. After cancer: the unmet supportive care needs of survivors and their partners. J Psychosoc Oncol 2007:25:89–104.
- Street RL, Gordon HS. The clinical context and patient participation in post-diagnostic consultations. *Patient Educ Couns* 2006;64:217–24.
- RCP. National lung cancer audit 2015 report. London: Royal College of Physicians, 2015. https://www.rcplondon.ac.uk/projects/outputs/ nlca-annual-report-2015. (accessed 03 Nov 2016).
- Lauer MS, D'Agostino RB. The randomized registry trial--the next disruptive technology in clinical research? N Engl J Med 2013;369:1579–81.
- Fröbert O, Lagerqvist B, Olivecrona GK, et al. Thrombus aspiration during ST-segment elevation myocardial infarction. N Engl J Med 2013;369:1587–97.



# Integrated care for resected early stage lung cancer: innovations and exploring patient needs

Jan Ho, Annette McWilliams, Jon Emery, Christobel Saunders, Christopher Reid, Suzanne Robinson and Fraser Brims

BMJ Open Resp Res 2017 4:

doi: 10.1136/bmjresp-2016-000175

Updated information and services can be found at: http://bmjopenrespres.bmj.com/content/4/1/e000175

These include:

**References** This article cites 37 articles, 6 of which you can access for free at:

http://bmjopenrespres.bmj.com/content/4/1/e000175#BIBL

Open Access This is an Open Access article distributed in accordance with the terms of

the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial

use, provided the original work is properly cited. See:

http://creativecommons.org/licenses/by/4.0/

Email alerting service Receive free email alerts when new articles cite this article. Sign up in the

box at the top right corner of the online article.

Topic Collections

Articles on similar topics can be found in the following collections

Lung cancer (9)

#### **Notes**

To request permissions go to: http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to: http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to: http://group.bmj.com/subscribe/