

## **Review of 'The Dream MDT':**

Measuring and improving high quality lung cancer outcomes

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#### Introduction

Multi-disciplinary teams (MDTs) are at the heart of delivering improved care for people with different types of cancers. Pooling together resources, clinical experience and insight into one functional team, MDTs were established to support the move away from generalist care, siloed working practices and poor communication between healthcare professionals (HCPs) and patients<sup>1</sup>. By working collaboratively they discuss and manage an individual patient's care and ultimately, secure the best possible outcomes for patients<sup>2</sup>.

Recognising the value of MDTs, existing clinical guidelines make clear that patients with a diagnosis of lung cancer should have their treatment and care discussed at a lung cancer MDT meeting<sup>3</sup>. Patients who are actively managed by a specialist MDT are more likely to receive higher quality, well-coordinated care and report a better overall experience<sup>4</sup>.

The UKLCC's *The Dream MDT for lung cancer: Delivering high quality lung cancer care and outcomes* report was published in November 2012<sup>5</sup>. Setting out an aspirational vision for how these teams are organised and operated, going beyond the existing clinical guidance for lung cancer, the *Dream MDT report* sought to identify and drive improvements in MDT practice.

Reaffirming the UKLCC's call for every lung cancer patient's case to be managed by a fully-equipped MDT in order to improve their chances of survival, this report revisits and builds upon the *Dream MDT report's* recommendations with the aim of:

- Driving further improvements in the quality of treatment and care available to lung cancer patients by assessing progress made across a range of the *Dream MDT's* recommendations
- Identifying examples of effective working and areas for improvements in current lung cancer MDT practices
- Promoting the effective joined-up working between primary, acute and community services to improve standards of care
- Establishing a gold-standard practice for lung cancer which clinicians would wish for their own families

Underpinning our assessment of progress in implementing the report's key recommendations, the *Review of 'The Dream MDT'* collates views and insights gathered from active MDT members from across the country and sets out a timely analysis of the latest available data on the performance of lung cancer MDTs from the most recently published Lung Cancer Service Profiles (LCSPs)<sup>6</sup>, National Cancer Patient Experience Survey (NCPES)<sup>7</sup> and the National Lung Cancer Audit (NLCA)<sup>8</sup>.

Whilst we have seen improvement in areas such as the percentage of patients which have an assigned Lung Cancer Nurse Specialist (CNS) and the proportion of trusts which have full membership of their specialist team, drastic improvement is still needed. This is especially true in areas such as the number of patients having to see their GP more than twice before being referred to hospital, the number of patients offered a written assessment and care plan and variation around the number of early stage lung cancer who undergo surgery. These are examples of areas where without improvement and MDTs being supported by the whole system, outcomes for lung cancer patients will continue to lag behind other cancers.

We hope this report will play a significant role in stressing the importance of MDTs across all four UK health systems and in securing the best possible outcomes for patients moving forward.







**Dr Mick Peake** 

Honorary Consultant and Senior Lecturer in Respiratory Medicine, Glenfield Hospital; Clinical Lead, National Cancer Intelligence Network (NCIN)

**Mr Richard Steyn** 

Consultant Thoracic
Surgeon; Associate
Medical Director –
Surgery, Heart of
England NHS
Foundation Trust;
Honorary Associate
Professor, University of
Warwick & Chair of the
UKLCC

#### **About the UKLCC**

Established in November 2005, the UK Lung Cancer Coalition (UKLCC) is a coalition of the UK's leading lung cancer experts, senior NHS professionals, charities and healthcare companies. Through our campaigning activity we aim to:

- Raise political awareness of lung cancer
- Raise the general public's awareness of lung cancer and especially encourage earlier presentation and symptom recognition
- Empower patients to take an active part in their care
- Improve lung cancer services in the UK

## **Contact details**

The UKLCC is keen to work with all interested organisations and bodies to improve the quality and outcomes of lung cancer treatment and care. For more information about our work and our partners, please visit our website (<a href="www.uklcc.org.uk">www.uklcc.org.uk</a>) or contact our secretariat:

Gail Ryan, UKLCC Secretariat Email: <a href="mailto:gailryan@redhotirons.com">gailryan@redhotirons.com</a>

Tel: 01675 477 065

## Membership and acknowledgements

The UKLCC's Clinical Advisory Group (CAG) is a panel of senior clinicians, each representing particular specialities involved in the care of lung cancer patients, from the time of first suspicion of the diagnosis through to palliative care. The members of the group are:

- Dr Andrew Wilcock, Clinical Reader in Palliative Medicine and Medical Oncology, Nottingham University Hospitals NHS Trust
- Dr David Bellamy, Retired GP with a specialist interest in respiratory medicine & member of the Primary Care Respiratory Society (PCRS)
- Dr Dean Fennell, Chair, Thoracic Medical Oncology, University of Leicester & Leicester University Hospitals NHS Trust
- Dr Frank Chinegwundoh, Chairman, Cancer Black Care
- Dr Ian Williamson, Consultant Respiratory Physician, Gwent Healthcare NHS Trust
- Dr John Reynolds, Consultant Radiologist, Birmingham Heartlands Hospital
- Professor Keith Kerr, Consultant Pathologist, Aberdeen Royal Infirmary
- Professor Michael Lind, Professor of Medical Oncology, University of Hull
- Dr Mick Peake, Honorary Consultant and Senior Lecturer in Respiratory Medicine, Glenfield Hospital; Clinical Lead, National Cancer Intelligence Network (NCIN)
- Dr Mike Snee, Consultant Clinical and Medical Oncologist, St. James's University Hospital, Leeds
- Mr Richard Steyn, Consultant Thoracic Surgeon; Associate Medical Director Surgery, Heart of England NHS Foundation Trust; Honorary Associate Professor, University of Warwick and Chair of the UKLCC
- Dr Robert Rintoul, Consultant Chest Physician, Department of Thoracic Oncology, Papworth Hospital NHS Foundation Trust

 Professor Stephen Spiro, Professor of Respiratory Medicine, University College London Hospitals

The CAG is also supported by leading patient and charity group members, including:

- British Lung Foundation
- Cancer Research UK
- Macmillan Cancer Support
- Roy Castle Lung Cancer Foundation
- Tenovus Cancer Care

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- Professor Keith Kerr, Consultant Pathologist, Aberdeen Royal Infirmary
- Dr Lori Calvert, Consultant Respiratory Physician, Peterborough and Stamford Hospitals NHS Foundation Trust
- Dr Robert Rintoul, Consultant Chest Physician, Department of Thoracic Oncology, Papworth Hospital NHS Foundation Trust
- Dr Thomas Pulimood, Respiratory Consultant, West Suffolk NHS Foundation Trust
- Dr Vincent Crosby, Consultant, Palliative Medicine, Hayward House Specialist Palliative Care Unit, Nottingham City Hospital

## **Key recommendations**

- 1. MDTs should ensure the lung CNS to lung cancer patient ratio is adequate to allow CNSs to be a core part of the MDT and be available for diagnostic, treatment and end of treatment appointments for all patients
- 2. GPs should ensure patients with signs and symptoms of lung cancer are urgently referred through the two week wait pathway, and proactively follow up with their patients to ensure they have received diagnostic tests and fully understand the information given to them
- 3. GPs should be regularly informed as to where their patients are along the care pathway and GPs should work with the MDT to ensure patients are told why they have been referred and be provided with information about their condition and treatment options
- 4. Patients with suspected lung cancer should be assessed at a dedicated rapid access clinic at the earliest possible opportunity. In addition, the diagnostic pathway should be designed by the MDT to encourage use of fewer, but higher value, tests to increase the likelihood that diagnosis and stage of the disease is assigned as quickly and effectively as possible
- 5. Full and appropriate membership of the specialist team and their regular attendance at the meetings should be of paramount importance to each MDT
- 6. MDTs should ensure patients are provided with written information about the type of cancer they have as soon as a diagnosis has been established and ensure the patient fully understands the information given to them and has an opportunity to ask any questions they may have
- 7. All MDTs for lung cancer patients should have at least one thoracic surgeon (undertaking a minimum one full day thoracic operating, minimum one full MDT per week and a thoracic surgical outpatient clinic with CNS support) as a core member
- 8. MDTs should work to ensure all patients are given appropriate treatment options before they begin their treatment regime and are fully involved in decisions about their care
- 9. MDTs should ensure all lung cancer patients are given information about any possible side effects of treatment in an easy to understand format
- 10. MDTs should always arrange a 'stock-take' meeting within a maximum of one month from the end of a patient's treatment to assess their experience of the care pathway, determine any other treatment provision and provide assurances of possible next steps
- 11. As a minimum, MDTs should routinely assess patients' supportive and palliative care needs around the time of diagnosis, on completion of primary treatment, when there is significant deterioration of symptoms and when it becomes clear that a patient is nearing death. A particular focus should be on improving the information required by patients and carers to ensure there is appropriate ongoing support at home.
- 12. At each stage of the care pathway the MDT should assess if a patient is eligible for a clinical trial and, if so, ask the patient whether they would like to participate

## **Lung Cancer Nurse Specialist (CNS) support**

As the *Dream MDT report* highlighted, CNSs play a vital role in the care of lung cancer patients as part of the wider lung cancer MDT with each of our clinical interviews only reaffirming their value and importance to patients and colleagues alike. Lung CNSs work differently to those caring for patients with other cancers, supporting patients from initial presentation through investigations to treatment, into palliative and supportive care, and are vitally important to ensuring both continuity of care and quality care. Indeed, insights from the clinical interviews underpinning this report identified the potential value of CNSs in providing a holistic approach to care, often trained in providing additional psychological and financial support.

As such, recommendation two in the *Dream MDT report* stated that "all lung cancer patients should be able to access lung CNS support and advocacy when they need it" and it is encouraging to see that the proportion of lung patients seen by a Lung CNS has improved to nearly 84 percent in the past year and the proportion of patients who have a lung CNS present at the time of diagnosis has risen from 61 percent to 65 percent in 2014<sup>9</sup>.

However, access to a lung CNS is not the only aspect which is important; the experience patients have with their CNS and the ongoing support they receive is of equal merit. Findings from the 2014 NCPES show an improvement in the reporting of lung cancer patient's experiences with Lung CNSs since the publication of the *Dream MDT report*. Lung cancer patients recorded the third highest scores of the 12 cancers surveyed when asked if they were given the name of a CNS in charge of their care – 92 percent – a one percent increase from 2013, with 75 percent noting how easy it was for them to contact their Lung CNS<sup>10,11</sup>.

Due to the important role lung CNSs play, these findings are encouraging. However, it is important to ensure all lung cancer patients are able to both access lung CNS support as well as feel the CNS is available and willing to answer any questions they have. In addition, trusts need to ensure lung CNSs are more involved with prediagnosis care of suspected lung cancer patients and not just become involved once a patient has started treatment.

Recommendation 1: MDTs should ensure the lung CNS to lung cancer patient ratio is adequate to allow CNSs to be a core part of the MDT and be available for diagnostic, treatment and end of treatment appointments for all patients

#### **Primary care**

As the *Dream MDT report* outlined, patients with lung cancer often fail to identify the key symptoms, or ignore them entirely, meaning they often present late to primary care. However, as recommendations six and seven in the *Dream MDT report* urged, GPs play an important role in ensuring patients with suspected lung cancer are urgently referred to specialist care as part of the two week GP referral pathway<sup>12</sup>.

Of concern are findings from the 2014 NCPES which found that 32 percent of lung cancer patients had to see their GP more than twice before being referred to hospital; a figure which has shown no improvement in the past year. This figure was the ninth worst of the 12 cancers surveyed by the NCPES and significantly higher than the

average of 25 percent of cancer patients who had to see their GP more than twice before being referred<sup>13</sup>.

The UKLCC recognises the difficulty GPs face in identifying the symptoms of lung cancer in patients. It can be difficult to differentiate the cause of non-specific symptoms such as a persistent wheeze, cough and asthma. However, given early detection initiatives such as *Be Clear on Cancer: lung cancer campaign* and the updated NICE guidelines on suspected cancer, we would hope lowering the threshold of suspicion for referral will help improve lung cancer detection rates in future<sup>14,15</sup>.

Importantly, where we have seen improvement is in the number of GPs using the two week wait urgent referral for suspected cancer. The 2013/14 LCSPs show the number of urgent GP referrals for suspected cancers has risen by 22 percent from 48,417 patients in 2012/13 to 59,237 in 2013/14<sup>16</sup>. Although it is difficult to identify a direct link to this significant rise in urgent referrals, campaigns such as *Be Clear on Cancer: lung cancer campaign* are expected to have had an impact on the number of patients presenting in some areas<sup>17</sup>.

In addition, where urgent referrals for suspected cancer have taken place, the number of patients diagnosed with lung cancer has decreased by three and a half percent to 21 percent in 2013/14. The number of urgent referrals for suspected lung cancer who are diagnosed with lung cancer, or the 'conversion rate', also varies significantly across trusts, with just three percent recorded at the Royal Free Hampstead NHS Trust compared to 49 percent at Liverpool Heart and Chest NHS Foundation Trust<sup>18</sup>. This stark variation indicates that cases of lung cancer are either being missed in primary care or the urgent referral route is being used overly cautiously.

Recommendation 2: GPs should ensure patients with signs and symptoms of lung cancer are urgently referred through the two week wait pathway, and proactively follow up with their patients to ensure they have received diagnostic tests and fully understand the information given to them



## **Primary – secondary care interface**

The role GPs can play in supporting patients should not end at a referral. As GPs are often the first and most important point of contact for patients, it is vital they are effectively connected to the MDT so that they are able to provide continual information to patients and their families.

The *Dream MDT report* called for a greater focus to be given to improving communication between primary and secondary care so that GPs can be kept informed as to where patients are along the care pathway. Since publication of the report, there has been an improvement in some aspects of communication between primary and secondary care. Encouragingly, in the 2014 NCPES 94.2 percent of lung cancer patients reported that they were given enough information about their condition and treatment<sup>19</sup>. Furthermore, general consensus from the clinical interviews was that new procedures in place helped ensure the continuity and clarity of communication between primary and secondary care. Although improvements can still be made, it is important to recognise where MDTs are working well, so we can identify where it is they need to make further improvements.

Recommendation 3: GPs should be regularly informed as to where their patients are along the care pathway and GPs should work with the MDT to ensure patients are told why they have been referred and be provided with information about their condition and treatment options

## **Respiratory medicine**

Best practice indicates that patients with suspected lung cancer should be assessed at a dedicated rapid access clinic at the earliest opportunity. In order to improve patient experience and the efficiency of their pathway, patients should have the minimum number of investigations to establish an accurate tissue diagnosis, the stage of disease and their fitness for treatment as quickly as possible.

Recommendation 11 in the *Dream MDT* emphasised the way in which a stage can be assigned whilst utilising fewer, but higher value, tests. This was a view expressed through discussions with clinicians, where it was made clear that increased and early access to CT and PET scans would save on unnecessary scans for patients. Encouragingly, since the *Dream MDT report* was published this has improved on two measures. According to the NLCA, the proportion of patients who received a CT scan prior to a bronchoscopy procedure has improved by just over three percent to 91 percent<sup>20</sup>. In addition, the proportion of lung cancer patients with a stage assigned has improved to 94 percent, a four percent rise since 2012/13<sup>21</sup>.

However, wide variation across trusts in assigning an appropriate stage is an issue which needs addressing. For example, the number of patients with a stage IIIB or IV assigned varies from 11 percent to 76 percent across England<sup>22</sup>. Although some variation is expected due to the prevalence of the disease, such high variation cannot continue if lung cancer patients are to be given the best possible chances of receiving appropriate and effective treatment.

Recommendation 4: Patients with suspected lung cancer should be assessed at a dedicated rapid access clinic at the earliest possible opportunity. In addition, the diagnostic pathway should be designed by the MDT to encourage use of fewer, but

higher value, tests to increase the likelihood that diagnosis and stage of the disease is assigned as quickly and effectively as possible

## MDT meeting structure for lung cancer patients

The *Dream MDT report* set out an aspirational vision for what an 'ideal MDT' should look like. Of equal importance to how successful MDTs are for patients, however, is how the different disciplines work collaboratively and provide positive outcomes for patients.

All patients should have their case discussed by an MDT consisting of a full range of expert clinicians from the fields of respiratory medicine, thoracic surgery, pathology, radiology, medical and clinical oncology, palliative care and lung cancer nursing. These individuals should be required to attend MDT meetings as part of their funded job plan with all MDTs being chaired by a clinician with an active interest in the disease. In 2014 95.6 percent of patients were discussed at an MDT meeting. This is high proportion which has remained static since the Dream MDT report was published and can still be improved<sup>23</sup>.

Recommendation 15 in the *Dream MDT report* stated that "care planning should be a two-stage process", but findings from the 2014 NCPES indicate that this is far from being achieved. In fact, it states that only 21 percent of lung cancer patients were offered a written assessment and care plan, the sixth best of 12 cancers surveyed and a one percent decrease on the previous year's figure<sup>24</sup>.

An important indicator of the success of an MDT for patients is whether a patient believes their assigned MDT worked well together across all of its disciplines. Positively, according to the 2014 NCPES, 65 percent of lung cancer patients said their MDT worked well together to "give them the best possible care", a figure which was above average across all cancers, but a decline on the 66 percent figure recorded in 2013<sup>25,26</sup>. Indeed, anecdotal evidence obtained through clinician interviews reaffirms the often positive and close workings between MDT members, contributing to the general high quality of MDT performance.

In addition to clinical roles within the MDT, it is just as important that support functions are available to provide assistance with communication, data analysis and administration. As recommended by the *Dream MDT report* in 2012, MDTs should have full membership and be "supported by an administrative and audit team". According to figures in the LCSPs, progress has been made since 2012. The proportion of trusts who have full membership of their specialist team has risen by 16 percent in the past year to 83 percent<sup>27</sup>.

When a diagnosis has been established, handling how a patient is told about their condition and their prognosis is a serious and delicate issue. MDTs can play an important role in making sure as much information as possible is available to patients when they are told they have cancer. Indeed, one measure of how well MDTs are performing in this regard is how many patients are given written information about the type of cancer they have. The most recent figures show that 64 percent of lung cancer patients were given written information, a figure much lower than the average of 72 percent for all cancer patients<sup>28</sup>. More worryingly the figure for lung cancer patients has declined by one percent since 2013<sup>29</sup>. An additional measure of how MDTs handle this sensitive time is whether patients understand the explanation given for what "was

wrong with them". On this measure, MDTs performed well, with 75 percent of lung cancer patients understanding the explanation given to them<sup>30</sup>.

Recommendation 5: Full and appropriate membership of the specialist team and their regular attendance at the meetings should be of paramount importance to each MDT

Recommendation 6: MDTs should ensure patients are provided with written information about the type of cancer they have as soon as a diagnosis has been established and ensure the patient fully understands the information given to them and has an opportunity to ask any questions they may have

## Surgery

The *Dream MDT report* highlighted the issue of the small number of thoracic surgeons in the UK supporting a larger number of MDTs; meaning it is extremely difficult for MDTs to have thoracic surgeon membership all year round. This may go some way to explaining the current variation in the proportion of patients with early stage lung cancer who receive surgery. According to the NLCA, the proportion of patients with early stage lung cancer who received surgery varied from 33.3 percent to 62.9 percent<sup>31</sup>. Since surgery can represent the best chance of treating lung cancer, these figures suggest a significant number of patients are not receiving the treatment that gives them the best chance of surviving as a result of a postcode lottery.

However, progress has been made in recent years in the proportion of Trusts that have full membership of their specialist team. As discussed above, this figure has risen by 16 percent in the past year to 83 percent, meaning progress is being made in ensuring all MDTs have membership across all of the appropriate specialisms<sup>32</sup>.

An important part of preparing a patient for surgery is providing them with information about their operation and/or treatment. Surgeons need to ensure they spend time with each patient and carer during the surgical consultation. As part of this it should be standard practice to provide written information to patients before their operation; however, findings from the 2014 NCPES showed 32 percent of lung cancer patients did not receive this information, dramatically different from the average of 24 percent of patients not receiving information across all cancers<sup>33</sup>.

Recommendation 7: All MDTs for lung cancer patients should have at least one thoracic surgeon (undertaking a minimum one full day thoracic operating, minimum one full MDT per week and a thoracic surgical outpatient clinic with CNS support) as a core member



## Medical and clinical oncology

After surgery, a Dream MDT will ensure all patients have its recommendations discussed with them by a relevant member of the MDT to consider the options for the next stage of treatment, the likely survival benefit and possible side effects of treatment. The setting and content of this discussion should be carefully considered and should ensure the patient is able to receive the information they require and ask any questions they may have.

Recommendation 25 in the *Dream MDT* stated "there should be an MDT discussion following completion of first-line surgical treatment, and patients should always be kept informed about the next step in their care pathway and their treatments options". An effective MDT will ensure patients are involved, in an appropriate way, in the development of their care and treatment plan and also keep them informed throughout the care pathway.

Measuring progress on this aspect of care, we found room for improvement in patients feeling involved in decisions taken about their care and treatment. Findings from the 2014 NCPES showed 72 percent of lung cancer patients felt "definitely involved in decisions about care and treatment"<sup>34</sup>. Although this is not a low percentage of patients compared to all other cancers, since 2012 there has been little improvement on this measure and if an MDT is running effectively this should be reflected in a higher percentage of patients.

As discussed, prior to beginning treatment a vital role the MDT should play is to discuss the different treatment options available with patients and any side effects that they can expect. Findings from the 2014 NCPES indicate that 82 percent of lung cancer patients were given a choice of different types of treatment before their programme began<sup>35</sup>. Whilst it is encouraging that a significant majority of patients are being offered a choice of treatment, this figure is both below the average of 86 percent for all cancer patients and marks a decline on the survey's findings from 2013 where 85 percent of lung cancer patients were offered choice of treatment<sup>36</sup>.

An essential role of the MDT is also to provide information to patients about the possible side effects of treatment. On this measure, it is encouraging to see 82 percent of lung cancer patients were provided written information about the side effects of treatment(s) prior to starting treatment. It is also important to consider how the possible side effects of treatment are explained to patients. According to 2014 NCPES figures, 76 percent of lung cancer patients are having the possible side effects of treatment explained in a way they could understand, marking progress since 2012, and ranking above the average score across all cancers surveyed<sup>37</sup>.

Recommendation 8: MDTs should work to ensure all patients are given appropriate treatment options before they begin their treatment regime and are fully involved in decisions about their care

Recommendation 9: MDTs should ensure all lung cancer patients are given information about any possible side effects of treatment in an easy to understand format

## **Borderline case management**

In general 6-8 percent of lung cancer patients are operable and deemed to be of low risk, with 50 percent having advanced cancer and 35-40 percent defined as borderline cases<sup>38</sup>. There is great potential to improve outcomes for those patients classified as borderline cases. The latest data shows there is currently a 50 percent variation in the number of patients with early stage lung cancer receiving surgery across England<sup>39</sup>.

As recommended by the UKLCC in the *Dream MDT report*, every MDT should "collect data for every patient, contribute this to the NLCA and publish an annual report including resection rates, other treatments given and patient outcomes". MDTs performed well against this recommendation, with data being recorded for 100 percent of patients who get to secondary care and the completeness levels of performance status, stage and treatment reaching almost 95 percent in the latest NLCA report<sup>40</sup>.

#### **End of acute phase**

Lung cancer patients can sometimes feel anxious and unsure of the future following their diagnosis and end of first-line treatment. Each MDT should aspire to arrange a 'stock-take' within one month from the end of a patient's treatment to ask the patient about their experience of the care pathway, provide an opportunity to ask any questions they may have and provide clear assurances of possible next steps. Lung CNSs are best placed to host this meeting, but support from the entire MDT will of course be necessary.

During this meeting, the lung CNS should ask about the patient's experience throughout the care pathway. Recommendation 27 within the *Dream MDT report* stipulated that the conversation should "go through what the patient knows, their prognosis, treatment options, point of contact and financial details". Encouragingly, progress has been made on this measure. When asked whether they received information about financial help or any benefits they might be entitled to, 70 percent of lung cancer patients said they received this information; which is significantly higher than any other set of cancer patients<sup>41</sup>.

In addition, relating to the beginning of the care pathway, when asked whether the results of diagnostic tests were explained to the patient in a way they could understand, 77 percent of lung cancer patients said they were. Although this is a high proportion of patients, MDTs should be striving to improve this figure to match cancers such as skin and breast who scored 83 and 82 percent respectively<sup>42</sup>.

Recommendation 10: MDTs should always arrange a 'stock-take' meeting within a maximum of one month from the end of a patient's treatment to assess their experience of the care pathway, determine any other treatment provision and provide assurances of possible next steps

## Supportive and palliative care

A Dream MDT must provide holistic supportive and palliative care throughout the patient's diagnostic and treatment pathway. This requires the MDT to proactively identify such needs so that appropriate support can be offered to both patients and carer(s).

Information provision is an important aspect of providing holistic care. Unfortunately, findings from the 2014 NCPES showed only 59 percent of lung cancer patient's families were "definitely given all information needed to help care at home". Furthermore, qualitative information ascertained from a number of clinical interviews indicated the lack, on a number of occasions, of palliative care physicians being in attendance at MDT meetings. Not only should patients, their family and carer(s) receive information about care at home but the care they receive should be tailored to their individual needs. Again, findings were poor for lung cancer patients. In 2014, 58 percent of patients said they were "definitely given enough care from health or social care services". This figure has significant room for improvement, especially as these figures are lower than for several other cancers<sup>43</sup>.

Recommendation 11: As a minimum, MDTs should routinely assess patients' supportive and palliative care needs around the time of diagnosis, on completion of primary treatment, when there is significant deterioration of symptoms and when it becomes clear that a patient is nearing death. A particular focus should be on improving the information required by patients and carers to ensure there is appropriate ongoing support at home.

#### Research and clinical trials

Information about, and access to, research and clinical trials is important for patients and MDTs in order for all treatment options to be explored and to further progress in the field of lung cancer and respiratory medicine.

One concern expressed through discussions with clinicians was a postcode lottery and inequity of patient access to research and clinical trials. It was noted that in many instances patients are keen to be involved in trials, and should the opportunity be engineered within their locality, they would take part appropriately.

Recommendations 29 and 30 in the *Dream MDT report* advised trusts to both advertise clinical trials publically to patients and ensure every MDT discussion includes an assessment of which clinical trials individual patients may be eliqible for.

Performance on these two measures have shown to be poor when compared to other cancers and previous years. In 2014 only 30 percent of lung cancer patients were asked whether they would like to take part in cancer research since diagnosis, the fifth worst of 12 cancer surveyed and a one percent decrease from 2013. Furthermore, of those patients asked, 58 percent went on to participate in research representing a four percent decline from the previous year and the worst figure across all cancers<sup>44,45</sup>. MDTs need to work to improve this figure and ensure all patients are given the opportunity to participate in research and clinical trials if they are eligible, and willing to do so.

Recommendation 12: At each stage of the care pathway the MDT should assess if a patient is eligible for a clinical trial and, if so, ask the patient whether they would like to participate

## **Conclusion**

Reflecting on our assessment of the current state of MDTs throughout England, there are reasons to be encouraged, room for improvement and some areas in drastic need of improvement.

It is important to recognise where improvements have taken place in the past two years since the publication of the *Dream MDT report*. The most notable improvement being with regards to patients increasingly assigned a CNS and a large majority of trusts securing full membership of their specialist team. This is only a stock take however, and there are always opportunities to improve further. In particular, too many patients are having to see their GP more than twice before being referred to hospital, and not enough patients are being offered a written assessment and care plan to support and signpost the care and treatment they should receive.

Moving ahead, the UKLCC is calling for all MDTs in the UK to consider the recommendations within this report and to continue to drive service improvement at their local level. We plan to undertake a further review in 2016 and annually thereafter. Only through continual monitoring, evaluation and service improvement will all patients receive the treatment they both need and deserve.

# Annex 1: Recommendations for driving progress in lung cancer MDT performance

**Recommendation 1:** The clinical MDT should be supported by an extended team that includes allied health professionals and social workers, to ensure patients' and carers' practical needs are addressed. This should be put in place from the time that detailed investigation is taking place by the specialist MDT in secondary care onwards through confirmation of diagnosis, to active treatment, chronic care and follow up support

**Recommendation 2:** All lung cancer patients should be able to access lung CNS support and advocacy when they need it throughout their whole patient journey to support their holistic needs

**Recommendation 3:** Lung CNSs should be involved with pre-diagnosis care of suspected lung cancer patients, from the point of detailed investigations in secondary care

**Recommendation 4:** Lung CNSs need to work closely with MDT coordinators, trackers and audit staff to ensure they are not taking on unnecessary administrative roles

**Recommendation 5:** Despite the financial pressures facing the NHS, the role of the lung CNS in ensuring optimal care for patients, must be protected

**Recommendation 6:** Where the results of a chest x-ray are normal and clinical suspicion of a diagnosis of lung cancer remains, GPs should consider an urgent referral under the two week wait pathway or have locally agreed arrangements for access to CT scans

**Recommendation 7:** Any chest x-ray or CT scan suggesting the possibility of a primary lung tumour, or a newly detected or growing nodule greater than 8mm in diameter should directly trigger an appointment in a rapid access lung cancer clinic

**Recommendation 8:** Communication between primary and secondary care is essential at all steps of the patient pathway. A greater focus should be given to improving communication between secondary and primary/community care in order that GPs are kept informed as rapidly as possible as to where patients (and their families) are along the care pathway

**Recommendation 9:** All suspected lung cancer cases should be dealt with by a respiratory physician with a specialist interest in lung cancer

**Recommendation 10:** Patients with a suspected lung cancer should be assessed at a dedicated rapid access clinic. Patients should have their CT scan before their respiratory consultation to provide sufficient time for the respiratory physician and radiologist to examine the scan results in a diagnostic MDT meeting prior to the first face to face meeting in clinic

**Recommendation 11:** The diagnostic pathway should be refined to encourage use of fewer, but higher value tests, likely to provide the diagnosis and stage of the disease in one step

**Recommendation 12:** Each patient should be assigned a dedicated chest physician with a specialist commitment to lung cancer to manage their care through the whole pathway

**Recommendation 13:** Specialist regional lung cancer MDTs should be established to deal with specified complex management problems and to ensure access to the latest advances in treatment which may not be available in all centres

**Recommendation 14:** The MDT should be properly supported by an administrative and audit team with proper IT facilities

**Recommendation 15:** Care planning should be a two-stage process – with diagnostic planning taking place ahead of the rapid access clinic and separately from the treatment planning MDT meeting

**Recommendation 16:** Each MDT should be able to draw on a team of specialist thoracic radiologists, and ideally two should be present at each meeting

**Recommendation 17:** All imaging should be reported by a specialist radiologist and there should be local agreement on the wording of reports and recommendations to clinicians

**Recommendation 18:** Adequate preparation time should be set aside before and after the MDT meeting and radiologists should be given adequate notice of cases

**Recommendation 19:** Lung MDT pathologists should have specialist thoracic expertise and access to super-specialist opinion as and when necessary

**Recommendation 20:** All MDTs should have a thoracic surgeon (undertaking a minimum one full day thoracic operating, minimum one full MDT per week and a thoracic surgical outpatient clinic with lung nurse specialist support) as a core member. He or she should be present at, or have adequate cover, for all meetings

**Recommendation 21:** All patients with a disease identified as borderline for treatment (3A or 3B), or who are borderline fit for surgery, should have their case assessed by at least one specialist thoracic surgeon within a specialist MDT

**Recommendation 22:** High quality video-conferencing should be available wherever required to improve working between specialist centres and DGHs

**Recommendation 23:** Thoracic surgeons should not work as single surgeons in a cardiac unit

**Recommendation 24:** Every lung cancer patient should have access to at least two dedicated thoracic oncologists offering cross-modality cover and expertise

**Recommendation 25:** There should be an MDT discussion following completion of first-line surgical treatment, and patients should always be kept informed about the next step in their care pathway and their treatments options

**Recommendation 26:** Every MDT should collect a minimum data set for every patient, contribute to the National Lung Cancer Audit and publish an annual report including resection rates, other treatments given and patient outcomes

**Recommendation 27:** A clinical stock-take/end of treatment assessment should be held, when the CNS has sufficient time to go through what the patient knows, their prognosis, treatment options, point of contact and financial details

**Recommendation 28:** SPARC or an equivalent tool should be used to assess patients' needs. The results should form the basis for care plans and referral to other services for specialist support

**Recommendation 29:** Every MDT discussion should include an assessment of which clinical trials individual patients may be eligible for

**Recommendation 30:** Data on which clinical trials are open for lung cancer patients and the record of trial entry by each centre should be made publicly available and easily accessible

#### **Annex 2: Data sources**

## **Lung Cancer Service Profiles**

Service profiles are based on Multi-Disciplinary Teams (MDTs), and bring together data from a wide range of routinely collected quality and service indicators. The indicators within the profiles have been developed in consultation with the relevant National Cancer Intelligence Network (NCIN) Site Specific Clinical Reference Group (SSCRG). They provide an 'at a glance' assessment of an MDT and enable the assessment and bench-marking of the services they provide. This, in turn, allows for objective dialogue about clinical practice and service delivery to support commissioning. The data in the profiles are updated annually based on the latest available information<sup>46</sup>.

http://www.ncin.org.uk/cancer information tools/profiles/serviceprofiles

#### **National Cancer Patient Experience Survey**

The Cancer Reform Strategy (CRS), published in 2007, first set out a commitment to establish a new NHS Cancer Patient Experience Survey Programme to monitor national progress and to drive quality improvements locally<sup>47</sup>. First implemented in 2010, and subsequently published in 2012 and 2013, the survey is, in 2014, now in its fourth iteration, covering all 153 acute and specialist NHS Trusts in England that provide adult acute cancer services<sup>48</sup>.

https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey

#### **National Lung Cancer Audit**

The National Lung Cancer Audit looks at the care delivered during referral, diagnosis, treatment and outcomes for people diagnosed with lung cancer and mesothelioma. The Audit measures the number of lung cancer cases within the UK; the range of treatments used; regional variations in treatments; and variations in outcomes with data collected from all hospital trusts within England treating patients with lung cancer or mesothelioma<sup>49</sup>.

http://www.hscic.gov.uk/catalogue/PUB16019/clin-audi-supp-prog-lung-nlca-2014-rep.pdf

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