

Patient priorities project lung cancer

Consultation activities report

December 2015



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Project background

The European Lung Foundation's 'Patient priorities – lung cancer project' was launched in January 2015 to develop patient-led guidance for patients and healthcare professionals based on priorities identified by patients and carers in Europe.

A patient advisory group was formed to guide the project made up individuals who had received a lung cancer diagnosis, family members/carers of someone with lung cancer and lung cancer patient organisation representatives. A number of countries were represented with members coming from the Czech Republic, Denmark, Germany, Ireland, Italy, the Netherlands, Poland, Spain and the United Kingdom.

The advisory group worked closely with members of the European Respiratory Society's lung cancer working group to input the patient perspective into their specific activities which included multi-disciplinary team (MDT) working in lung cancer care.

Actions/activities

As part of the project, a number of consultation activities took place with patients, carers and patient organisation representatives across Europe to inform the guidance.

This report highlights the main findings from these consultation activities:

1. Meetings were held in February and April 2015 with the lung cancer patient advisory group to discuss and identify patient priorities for lung cancer treatment and care (see page 5).
2. A workshop was held with the lung cancer patient advisory group (12 participants) in June 2015 in Brussels, where views were shared about what was of most importance to people with a diagnosis of lung cancer and their carers/family members around treatment, care and multi-disciplinary team (MDT) working (see pages 6-9).
3. A questionnaire was distributed to lung cancer patient organisations in July-Aug 2015 to gather an overview of MDT working, or other healthcare models used in their country (see pages 10-12).
4. An online questionnaire was promoted to individuals diagnosed with lung cancer and their family members/carers across Europe from August - October 2015 to corroborate and add to these findings (see pages 13-27).
5. A second workshop bringing together patients and healthcare professionals (18 participants) took place at the ERS International Congress in Amsterdam in September 2015 to discuss further MDT working and priorities for treatment and care (see pages 28-33).

Summary of key consultation findings

The main points emerging from the consultation activities are as follows:

1. Project outline

Lung cancer patient advisory group

ELF recruited to a patient advisory group in January 2015 which grew from 12 initial members to 16: made up of individuals diagnosed with lung cancer, family members/carers of an individual diagnosed with lung cancer and lung cancer patient organisation representatives. Members joined from the following countries: Czech Republic, Denmark, Germany, Ireland, Italy, Netherlands, Poland, Spain and United Kingdom.

Meetings and discussions

A first teleconference meeting took place in February 2015 where discussions around the project's aims, objectives and plans were discussed. It was recognised that the opportunity for patients to work together with ERS healthcare professionals through this project was of great value in raising awareness of what matters most to patients. A closed Facebook group was set up following this meeting for members to continue ongoing discussions.

In April, the patient advisory group met in Brussels to discuss the project in more depth was clear that guidance developed should signpost to quality information already in existence rather than re-inventing the wheel. The following initial patient priorities emerged:

Patient priorities for lung cancer treatment and care

- Knowledge of best treatment/therapy options available to patients
- Holistic care to meet both physical and psychological needs
- Good communication and understanding between the doctor and patient
- Good quality, accessible information at all stages
- Information on the most recent advances in research, including personalised medicine and access to clinical trials
- Educating and empowering patients to advocate for themselves
- Collaboration with healthcare professionals to achieve change

At the heart of these priorities *“a quality doctor-patient relationship”* was identified.

Consultation workshops and survey

Wider consultation plans were discussed so that the priorities emerging from the patient advisory group could be tested with a wider pool of individuals with experience of lung cancer. Two workshops were planned: the first with patients/carers to focus on ‘a quality doctor-patient relationship’ which would inform a survey to be disseminated in Europe. A

second workshop would be held with patients and healthcare professionals at the ERS International Congress in Amsterdam to discuss consultation findings and priorities together.

2. Patient priorities workshop, 11 June 2015, Brussels

Brought together 13 individuals with experience of lung cancer to explore:

- a) Quality healthcare professional/patient relationships: interactions with healthcare professionals.
- b) Multidisciplinary team (MDT) working in lung cancer care across Europe.
- c) Development of a patient priorities lung cancer website.
- d) Research priorities for lung cancer.

a) Interactions with healthcare professionals

Participants shared their individual experiences of interacting with healthcare professionals throughout their lung cancer experience and highlighted what they had found helpful and unhelpful. Key messages were formulated for healthcare professionals and patients to support the development of quality healthcare professional-patient relationships.

Messages for healthcare professionals:

1. Treat us with respect, warmth and real care.
2. Treat us as individuals – our lung cancer experience is not the same.
3. Appreciate that we are the experts in living with lung cancer every day.
4. Be sensitive to our predicament and “be with us” on our journey.
5. Offer us positivity and hope about what can be done.
6. Communicate clearly and avoid medical jargon.
7. Give us the level of information we want – one size does not fit all.
8. Provide fuller information on treatments, with options and choice however limited.
9. Follow up verbal exchange with written information by post/email.
10. Encourage us to ask questions and check with us: “what do you want to know?”

Messages for patients:

1. Assert your right to be respected as a person and not as a medical case: “I am a person not symptoms”.
2. Tell the truth.
3. Prepare for appointments and consultations e.g. write down questions/issues.
4. Tell the doctor what you want to know – the professionals are there for you.
5. Ask the doctor what you should do.

6. Do not be scared to ask anything – there are no stupid questions about cancer.
7. Ask for further explanation if you do not understand something.
8. Help the doctors to solve their issues if possible.
9. Challenge the doctor if you want to question something they have said.

b) Multidisciplinary (MDT) team working across Europe

Three members of the ERS lung cancer working group joined by Skype to introduce the work they were doing around multidisciplinary team (MDT) working in lung cancer care and how they were keen to incorporate the patient experience and produce a joint statement for publication in a European journal to help improve lung cancer services.



A summary of the patient discussions which followed are outlined below:

General views

It was felt that the MDT approach is good, but that having it in place does not ensure that patients are treated holistically. Having timed pathways also makes patient involvement harder. Only when the patient has been given enough information can they realistically become part of “the team”. Mutual respect is key and attempts made to address the balance of power to ensure patients can be equal in the relationship, informed and involved in decision-making and treatment. Developing the ‘community’ aspect of the doctor-patient relationships by including other professionals could help to redress this balance.

The patient needs to understand why each professional is part of the team and that more lung cancer specialist nurses are required throughout their treatment and care. Having access to counselling services would also be beneficial. Patients need to be given the ultimate decision making over options provided by professionals if they are not to be disempowered.

It is also important to provide prompt appointments for chemotherapy and better co-ordination, especially where travel is concerned.

It was felt that there was a lack of medical services and contact from professionals following treatment when patients can feel very isolated and that more contact would be beneficial in the post-treatment stage. Hospitals could possibly improve the care they provide by contracting services or making closer links with lung cancer patient organisations.

The provision of further training, supervision and psychological support for doctors was felt to be important, so that they can deliver bad news sensitively as well as, learn how to deal with this difficult task and any impact it may have on themselves. It was felt that learning from nurses on how to communicate well could be useful.

It was evident through the discussions that there is clear variation in quality and approach *within* countries, which determines treatment provided, and therefore it would be good to have an advocate in each country to cascade patient principles down from European level as an outcome beyond the remit of this project.

Information about patient to be provided to the MDT:

Information that patients want provided to MDT includes:

- Details about their social background, including any caring responsibilities and support that is available to them.
- Details of how the patient feels e.g. “I can walk downstairs”, “I am eating more” and their mobility status.
- The emotional/mental health of the patient is very important to assess as this might indicate other professionals appropriate to include on the MDT.
- The employment status of the patient, and possibly financial information should be included, although there was disagreement within the group as to whether including this detail could lead to treatment decisions made on the ability of the patient to pay.
- A suggestion was made to design a standard, simple questionnaire for the patient to fill in, early in the pathway, to capture the above information.



Which professionals should be involved in the MDT

It was felt that this should not be set rigidly as it will depend on the patient’s needs at each stage and should be made up of those professionals that are most relevant to the patient at the time. It was felt however, that it would be useful to define the minimum requirement for MDT working.

It was felt that both home care and palliative care teams should be involved at early stages, as well as mental health and social care liaison if and when required. The patient should be informed as to which professionals are on the MDT and have the opportunity to question it.

There should be a consistent contact point within the team for the patient. A suggestion made was for an attending doctor/nurse who knows the patient well to be appointed to keep the patient informed and to represent the patient. It was also suggested that a patient navigator be appointed to organise appointments and help with organisational aspects, and who could be contacted by the patient at any time.

Information that patients want communicated out of the MDT

It was felt that verbal feedback from the patient's consistent contact should be provided where possible, although not to postpone feedback if this contact was not available. It is essential that all verbal feedback be followed up promptly with a written report sent to the patient by email or post. The report should be clearly written and concise using language understandable by the patient.

If there needs to be delivery of bad news, around diagnosis or treatment, then patients' request that it be given in the most positive way possible and at the beginning of the meeting. There were both positive and negative experiences of this within the group but in general, it was felt that professionals could improve this area so that they deliver a diagnosis sensitively and are able to manage a range of patient responses to it appropriately. It was also felt important to increase awareness with professionals that the psychological aspect of diagnosis also has an impact on family members.

It was felt important that all relevant professionals involved in the patient's care should be kept informed, including the family doctor and relevant co-morbidity specialists, and that a copy of the MDT report should be sent to them. Ideally, patients would like to see the report before it was sent out, although it was recognised that this may not be feasible, and that a standard report template should be designed which would also include details of meetings and action points.

Specific information patients would like to see included in the MDT report is:

- How our condition/treatment is progressing (this needs to be the first thing).
- Concentrate on positives and if there are negatives, focus on how they can be dealt with.
- Always include choices however limited.
- Include what the patient has said previously, e.g. information from the questionnaire they complete.
- Explanations for unsuitable options should be given, e.g. if not suitable for surgery.
- Explain how psychosocial, home care and palliative care needs will be addressed.
- Use simple graphics for visual representation of regular tests for comparison.
- Provide contact for follow-up questions by phone or email.
- Link with any other related reports and have continuity with previous MDT reports.

c) Development of a patient priorities lung cancer website

The proposal to develop a lung cancer patient priorities website to signpost to quality information in Europe was discussed. Different user profiles were developed and key elements to incorporate within the site were as follows:

- A professional and welcoming site for patients.
- Provide basic information about treatment/therapies available with option to access more advanced information.
- Include patient stories and experiences that offer hope.
- Link to reputable websites with the best information
- Summarise latest research into accessible language.
- Provide links to support groups and organisations in Europe.
- Use illustrations instead of too many words.

d) Research priorities

Areas defined as key for future lung cancer research are listed below (not in any priority order):

- Links with other respiratory conditions.
- Links with environmental issues.
- Role of key contact and what difference it makes to treatment/survival.
- Psychosocial effects of diagnosis and coping strategies on different personality types.
- Stigma associated with lung cancer – why there is little/biased media coverage?
- What therapy provides the best response? e.g. identify the characteristics of patients who benefit most.
- Better understand what drives tumours.
- Survivorship with lung cancer – what are the demographics?
- Why lung cancer is missed in many people and only picked up when presenting at Accident & Emergency at hospital e.g. recognition of symptoms/screening.
- The patient's view of CT-scan screening.
- Accuracy in recording cause of death when co-morbidities present.
- Hormonal impact and increased incidence of adeno-carcinoma.
- Understanding more about never/non-smokers with lung cancer.

3. Questionnaire findings: lung cancer patient organisations July-Aug 2015

Introduction

At a workshop with the ELF lung cancer patient advisory group in June 2015 in Brussels, we gathered views about what was of most importance to people with a diagnosis of lung cancer and their carers/family members around treatment, care and multi-disciplinary team (MDT) working.

A questionnaire was disseminated to lung cancer patient organisations in Europe during July-August 2015 to gather an overview from their perspective of the general awareness about MDT working in their country, or other health models in operation. A summary of the findings is below. The questionnaire was circulated to patient organisations specialising in lung cancer and seven responses were received from the following five organisations:

1. AEACAP – Fundacion MAS QUE DIEAS, Spain
2. Association for the fight against Lung Cancer, Poland
3. Cancer Patients' Association of Slovenia
4. Swiss Forum Lung Cancer
5. Women Against Lung Cancer in Europe (WALCE), Italy

Key findings

ITALY (Women Against Lung Cancer in Europe (WALCE) – 1 respondent

- Inconsistency of teams operating throughout the country with many facilities not organised through MDT.
- Long waiting times for visits to specialists.
- Quality of service varies from hospital to hospital and region to region. There are some excellent specialist centres for lung cancer treatment all over the country which includes the psychological aspect for patient and family.
- *Biggest improvements needed:* More specialised centres all over the country, organise centres for patients' families; educate local doctors more.
- *Inform health care professionals at European level that:* more resources need allocating for primary prevention campaigns and raising awareness.

POLAND (Association for the fight against Lung Cancer) – 3 respondents

- MDT works in Poland particularly in larger medical centres where tests are complex and patients are diagnosed.

- There are long waiting times to access specialists and follow-up tests in smaller cities leading to late diagnosis. Patients are being directed to other medical care units and have no leading doctor.
- If there is no progress after the second round of chemotherapy, there is no offer of further treatment.
- Care for patients is good, especially for those who have no complications. With secondary tumours or complications, the medical care is not always good enough.
- *Biggest improvements needed:* Setting complex medical care for the patient from diagnosis until after convalescence, including periodic check-ups. Legal and financial solutions for treatment of rare cancer types and therapy for patients after secondary tumour treatment.
- *Inform health care professionals at European level that:* Patients should not be put to one side. Need for better access to information about innovative therapies.

SLOVENIA (Cancer Patients' Association of Slovenia) – 1 respondent

- Have social security system with patient's GP in charge of basic health problems and referral to specialists. In practice, different specialists perform majority of lung cancer patients' care. Collaboration between the specialists and GPs is not optimal.
- Early diagnosis is a major problem.
- Social security system is beneficial but health system waiting times, referral policies, local doctor responsibilities, access to novel drugs, psychosocial support and rehab, suffer from major shortages and challenges.
- The MDT model is beneficial; however patients should be involved in MDT discussions and decisions.
- *Biggest improvements needed:* early diagnostics, better organisation of health care, access to novel procedures and drugs, improved rehab and psychological support during and after treatment
- *Inform health care professionals at European level that:* A close collaboration of oncology field professionals, health authorities and patients/civil societies is urgently needed in order to raise the bar of expected cancer care and survival outcomes in lung cancer to the levels already achieved in Europe for colon and breast cancer.

SPAIN (AEACAP – Fundacion MAS QUE DIEAS) – 1 respondent

- MDT is familiar in Spain with a range of professionals involved in lung cancer care in order to meet the physical, psychological and social needs of patients.
- The MDT model is beneficial. The ideal is a team of different healthcare professionals discussing and working with the patient and for the patient. Including the importance of psychological and social support to increase quality of life of patients and relatives.

- Co-ordinated health assistance is needed to ensure access to services such as social work, psychological support or a nutritionist.
- There are challenges around high cost of innovative therapies and therefore some administrative barriers to access treatments.
- There is a need to accelerate the time from when a drug is approved by the EMA until it is commercialised; currently this is over one year.
- More specialised training of local doctors so that they can identify lung cancer symptoms earlier.
- *Biggest improvements needed:* More clinical and translational research, more transparency and less time in the national reimbursement and pricing approval process, and make progress about quality of life during treatments.

SWITZERLAND (Swiss Forum Lung Cancer) – 1 respondent

- MDT does not involve medical care for outpatients in private practices. This needs to be changed and for all medical care involved working externally from the nearest lung cancer specialised clinic.
- The MDT model is most important to all cancer patients and severe diseases. But it is far from being a successful model at the moment.
- Patient pathway is not very structured. In MDT the patients are not involved at all.
- Awareness about MDT should be improved and onco-psychologists involved sooner.
- There is no specialised lung cancer care – following first diagnostic x-rays and suspicion of lung cancer – patient will be sent to a lung specialist. If diagnosis confirmed, sent to oncologist – are very few specialised clinics.
- No quality criteria for clinics or MDT, so clinics can describe themselves as specialists in lung cancer without checks. Do not have any specialised cancer nurses.
- Since lung cancer has poor prognosis and is perceived to be self-caused, many health insurance companies say whether the patient will get their treatment paid or not.
- Current system has improved in last 10 years, but is not well organised or structured. Main problem is patient information, as no-one is responsible for this.
- Lung cancer is very much a taboo and stigmatised in Switzerland.
- Switzerland does not have specialised rehab; patients can only go to rehab if there is a chance they can get back to work.
- *Biggest improvements needed:* Better structuring of the patient pathway for patients from the point of ‘suspicion that might have lung cancer’; quality certification of specialised lung cancer clinics and private practice doctors
- *Inform health care professionals at European level that:* The needs and understanding of MDT is completely different to what the medical side feels they are doing or offering (based on views expressed at two Swiss cancer congresses and many expert meetings).

4. Questionnaire findings: patients and carers Aug-Oct 2015

a) Introduction

Background

At a workshop with the ELF lung cancer patient advisory group in June 2015 in Brussels (12 participants), we gathered views about what was of most importance to people with a diagnosis of lung cancer and their carers/family members around treatment, care and multi-disciplinary team (MDT) working.

A questionnaire was then disseminated to individuals throughout Europe during August/September 2015 to corroborate and add to these findings.

Dissemination

The questionnaire was disseminated online in the following 15 languages: Czech, Danish, Dutch, English, Flemish, French, German, Greek, Italian, Norwegian, Polish, Portuguese, Russian, Spanish and Swedish. It was promoted through ELF and ERS member networks, newsletters and social media channels.

Response

895 individuals accessed the survey in total and of these 372 met the inclusion criteria e.g. an individual with a diagnosis of lung cancer or a family member/carer of someone with lung cancer. Exclusions included individuals with a different diagnosis, healthcare professionals, those with a general interest in lung cancer and individuals located from countries outside of Europe. There were a large number of responses to the Spanish survey from individuals living in Latin America.

Of the responses we analysed, 135 (36%) identified themselves as an individual with a diagnosis of lung cancer and 237 as family members/carers (64%).

Demographics

Characteristics	Patient responses	Carer responses	All responses
No. of eligible respondents	135 (36%)	237 (64%)	372
Type of lung cancer	78 (62%) Non-small cell lung cancer 23 (18%) Small cell lung cancer 14 (11%) Do not know 12 (9%) Other		
Lung cancer stage of patient	12% Diagnosed and waiting for further tests 12% Undergoing first round of treatment 10% Undergoing later rounds of treatment 40% Finished treatment/in remission 11% In palliative care 4% Did not know 11% Other		
Survey language	29% German 16% English 10% Polish 10% Spanish 9% French 7% Norwegian 7% Danish 5% Greek 2% Netherlands 2% Swedish 1% Flemish 1% Italian 1% Russian	40% English 13% German 12% Greek 9% Spanish 7% Polish 6% Norwegian 4% French 2% Russian 2% Portuguese 1% Dutch 1% Flemish 1% Czech 1% Italian 1% Swedish	32% English 19% German 9% Greek 9% Polish 9% Spanish 6% French 3% Danish 3% Norwegian 2% Dutch 2% Flemish 2% Russian 1% Portuguese 1% Czech 1% Swedish 1% Italian
Gender	51% Female 49% Male	76% Female 24% Male	67% Female 33% Male
Age range	30% 50-59 27% 60-69 17% 18-39 16% 40-49 16% 70-79 4% 80 and over 0% under 18	38% 30-39 21% 50-59 21% 40-49 13% 60-69 3% 70-79 3% under 18 1% 80 and over	27% 18-39 24% 50-59 19% 40-49 18% 60-69 8% 70-79 2% under 18 2% 80 and over

b) Condition, treatment and care

Length of time to refer for tests from family physician:

55%	Within 2 weeks
11%	Within 1 month
10%	Did not refer
3%	6 months – 1 year
7%	1+ years
5%	1-3 months
6%	3-6 months
3%	Do not know

Specialism of physicians leading treatment

52% (63 participants) identified the physician leading their treatment as an oncologist and 40% as a pulmonary/respiratory physician/lung physician, 5% described them as 'Other' and 3% did not know.

Services

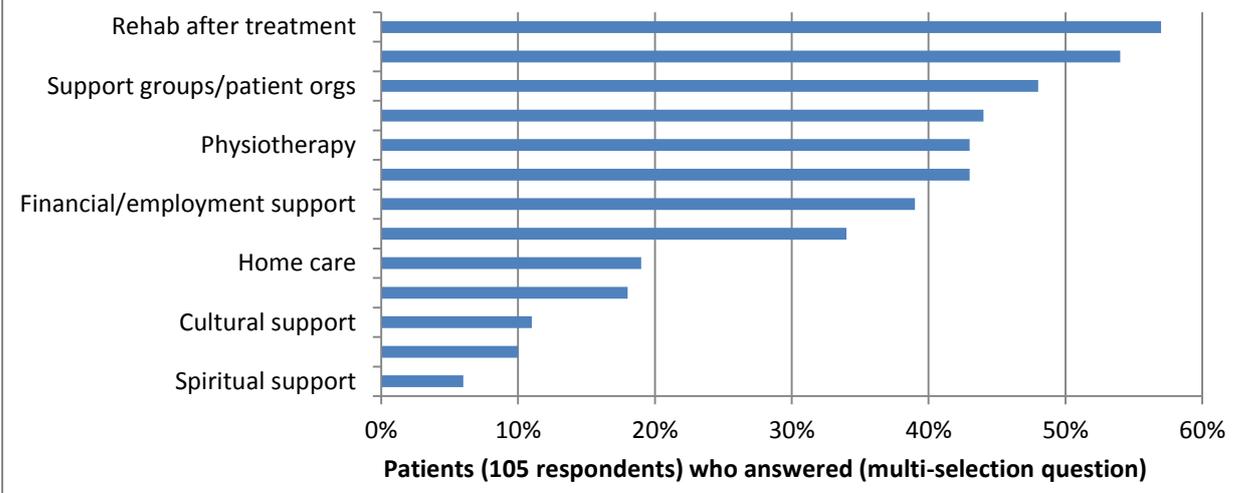
The services identified as of most importance for people diagnosed with lung cancer and carers are in descending order as follows (see also graphs on page 16):

Important services identified by 105 patients who responded to this question were (more than one could be selected): rehabilitation following treatment (57%); psychological counselling (54%); support groups/patient organisations (48%); peer support (44%); physiotherapy (43%); palliative care (43%); financial/employment support (39%); nutrition/food advice (34%); home care (19%); rehabilitation before treatment (18%); cultural support (11%); occupational therapy (10%) and spiritual support (6%).

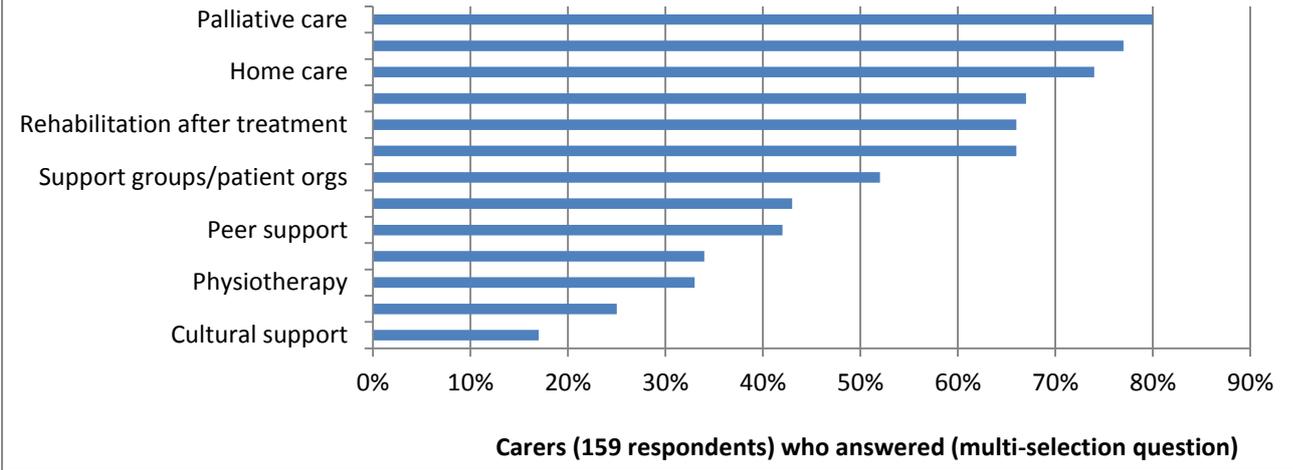
Identified by carers: palliative care (80%); psychological counselling (77%); home care (74%); nutrition advice (67%); rehabilitation after treatment (66%); financial/employment advice (66%); support groups and patient organisations (52%); rehabilitation before treatment (43%); peer support (42%); spiritual support (34%); physiotherapy (33%); occupational therapy (25%) and cultural support (17%).

The main differences were that carers identified palliative care planning as the most important whereas this was joint 5th most important to patients. However, as 40% of the respondents identified themselves as having finished treatment/in remission, this may account for this. Both groups identified psychological counselling as 2nd most important and home care, nutritional advice and spiritual support was of more importance to carers.

Most important services for patients



Most important services for patients (carers' view)

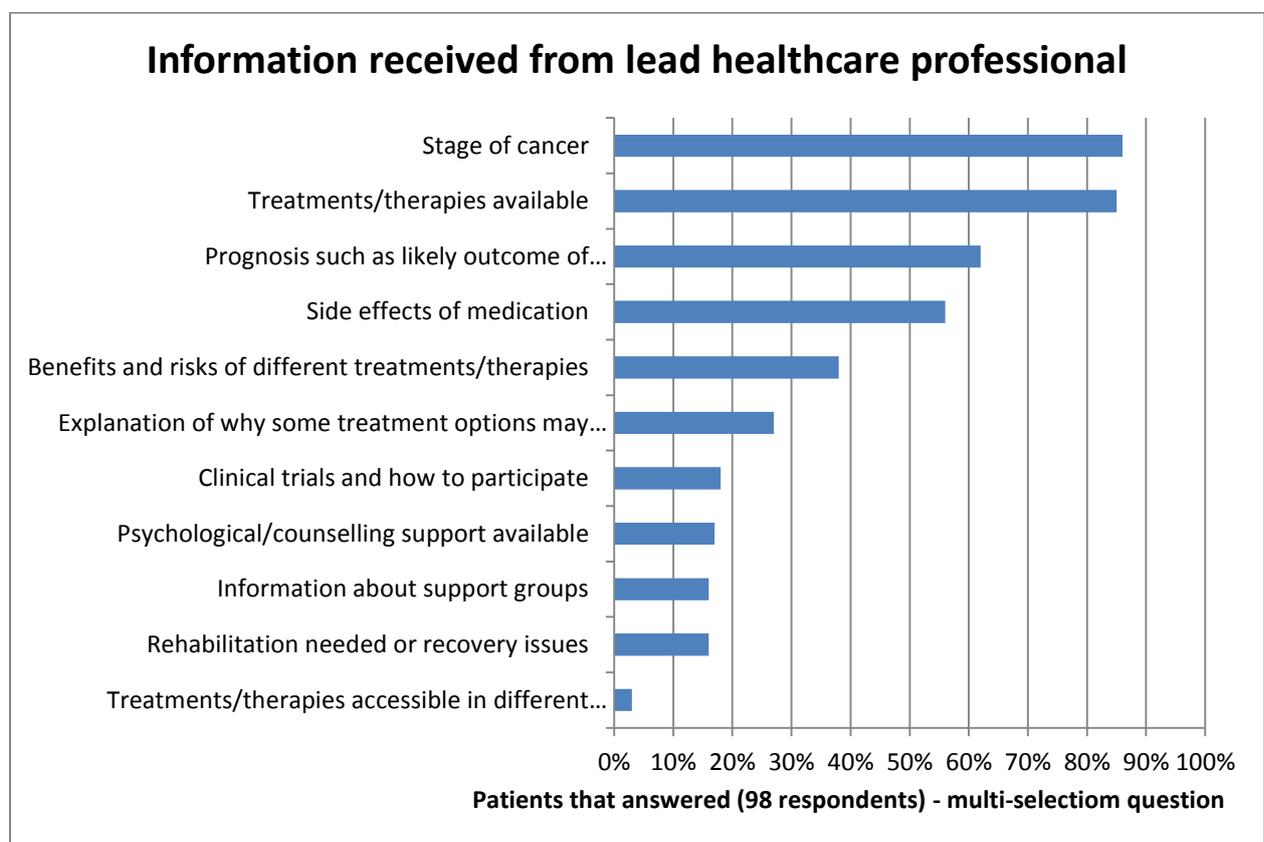


c) Interactions with healthcare professionals

INFORMATION NEEDS

Information received

The questionnaire asked which types of information patients and carers had received from the healthcare professional leading their care. The patient respondents indicated that over 50% received information about treatments/therapies available, the stage and prognosis of their cancer, and side effects of medication. The remaining types of information were less commonly received.



When looking at which services are important and what information was provided to patients, the findings suggest that there is a need for healthcare professionals to provide more information about rehabilitation and psychological support.

Information needs of carers/family members

The questionnaire asked an open question to carers and family members to state if there were any additional information needs that they themselves would find important. The most commonly identified themes were:

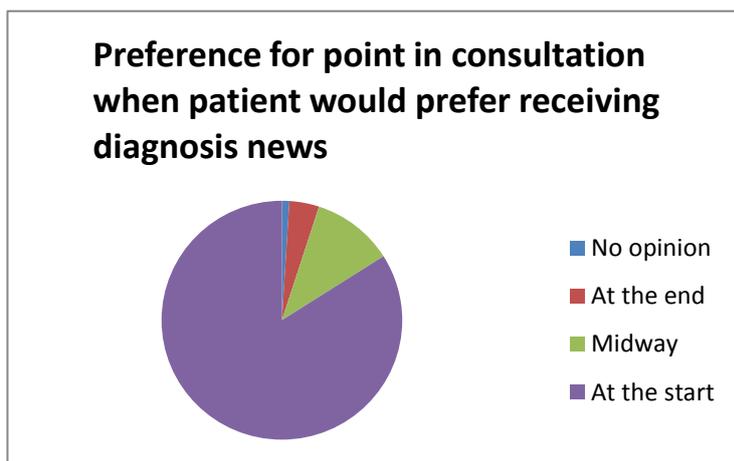
- More detail about what to expect throughout a patient's treatment
- How to cope with the shock of diagnosis and to best support the patient through the stages of reaction and treatment
- Contact information, e.g. contact details for out of hours
- Practical help available, e.g. assistance in travelling for treatment; family support
- How to look after yourself while caring
- Palliative care options and home care support

Communication of diagnosis

How individuals living with lung cancer feel about their diagnosis can be affected by the timing of when they are told their diagnosis.

To try and capture how respondents feel about this, the survey asked at what point in the consultation meeting, would individuals prefer news about the diagnosis to be given. Of 111 patients that answered this question they stated that they would prefer to be told their diagnosis:

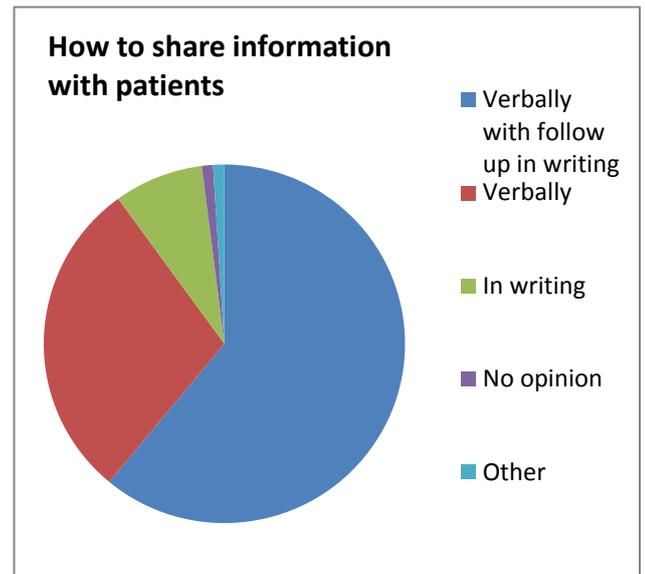
At the start	84%
Midway	11%
At the end	4%
No opinion	1%



Sharing information about treatment/care plan

Patients were asked how they would like their treatment/care plan to be shared with them; of 108 responses:

Info verbally with follow-up in writing	61%
Info shared verbally	28%
Info in writing	8%
No opinion	2%
Other	1%



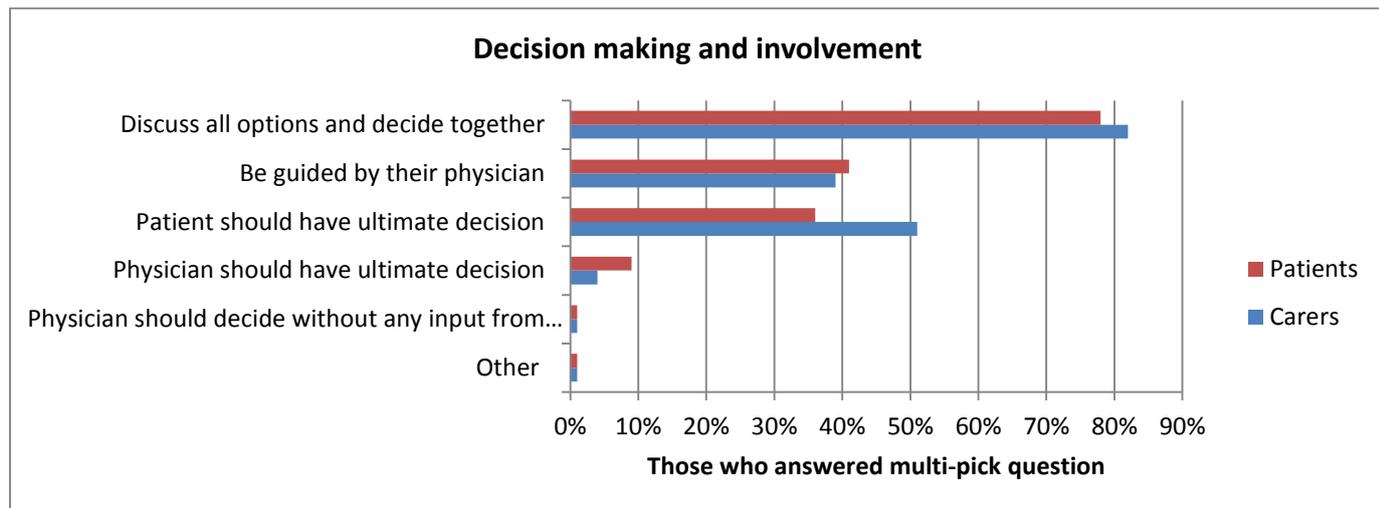
Respondents explained:

“It’s a stressful time, so even if we’ve heard stuff we can forget, and with medical terms, it’s useful to have this in writing to make further investigations later” and a positive experience highlighted by one patient was *“my diagnosis was sent to me by email with very positive extras added from the oncologist”* and *“it needs objective factual information - no glossing over - the patient should and must have information to help make decisions”* and *“please give information in writing, you cannot possibly process everything that it said when you are in such an emotional state”*. It was stressed that plain lay language be used consistently.

DECISION MAKING

The importance of discussing all options and deciding together was identified by over 75% of both patients and carers as being of most importance from the options given (see graph below).

A comment expressed was: *“the most important issue is respect the patient and consider involving them in all decisions, after all it is the patient who has the cancer”*.

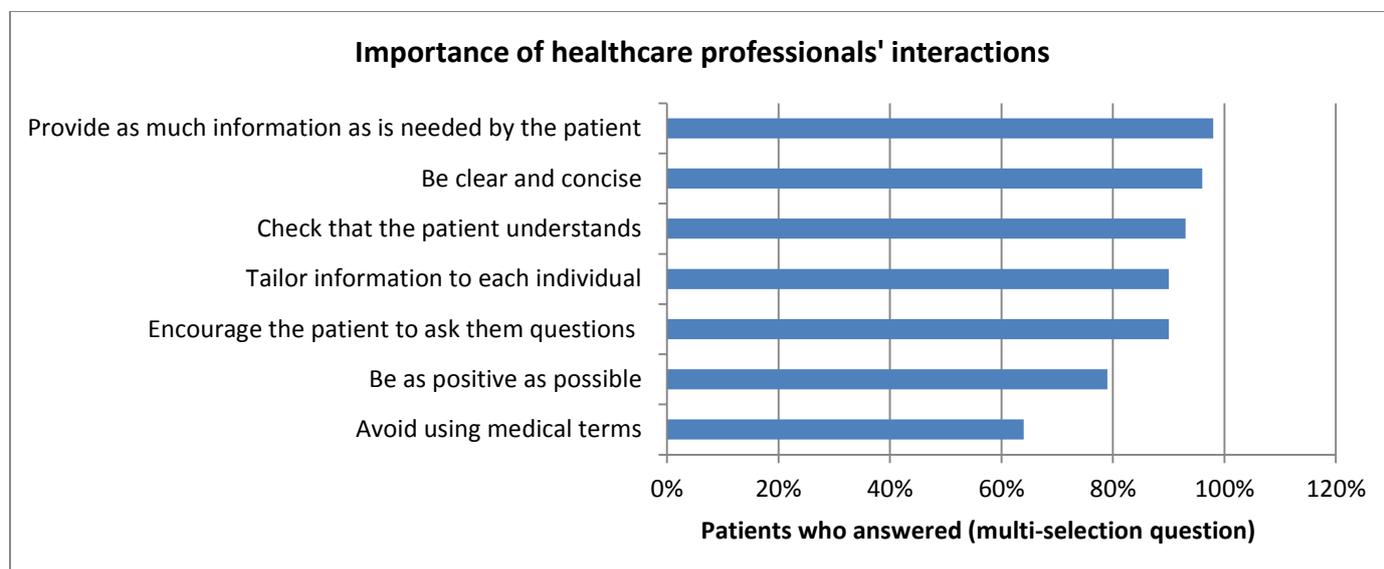


Involvement of family physician

87% of patient respondents (111 who answered this question) felt that it was important for their family/local physician to be kept informed of progress. This was similar to carer respondents (162) of which 83% indicated the importance of this. Comments included *“Continuity of care wasn't good. Each element was ok but their communication between one another was not good. They seemed to be relying on the patient/family to do this. There should be a better system to keep the GP in the loop”*.

IMPORTANT INTERACTIONS BETWEEN HEALTHCARE PROFESSIONALS AND PATIENTS

The importance of the following for healthcare professionals to do is highlighted in the chart below by patients: 98% wanting healthcare professionals to provide as much information as is needed by the patient; 96% wanting healthcare professionals to be clear and concise; 93% want healthcare professionals to check they have understood; 90% want information tailored to them; 90% wanted healthcare professionals to encourage them to ask them questions; 79% wanted healthcare professionals to be as positive as possible and 64% to avoid using medical terms. Although 64% wanted medical terms to be avoided it was noted that it could be important for medical terms to be used but that the healthcare professionals should then translate into lay language. This is important because if a patient wants to seek further info they may need to use the medical term.



Point of contact

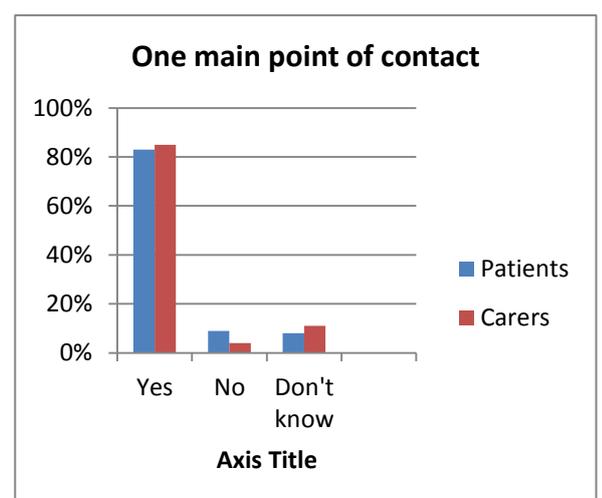
83% of patients and 85% of carers felt it was important that they had one main person/point of contact at each stage of the lung cancer experience, e.g. care co-ordinator/patient navigator (see chart to the right). Some comments expressed included:

“Communications can be complex – this would help navigate the internal maze on behalf of patients” and

“My specialist has played that role perfectly” and

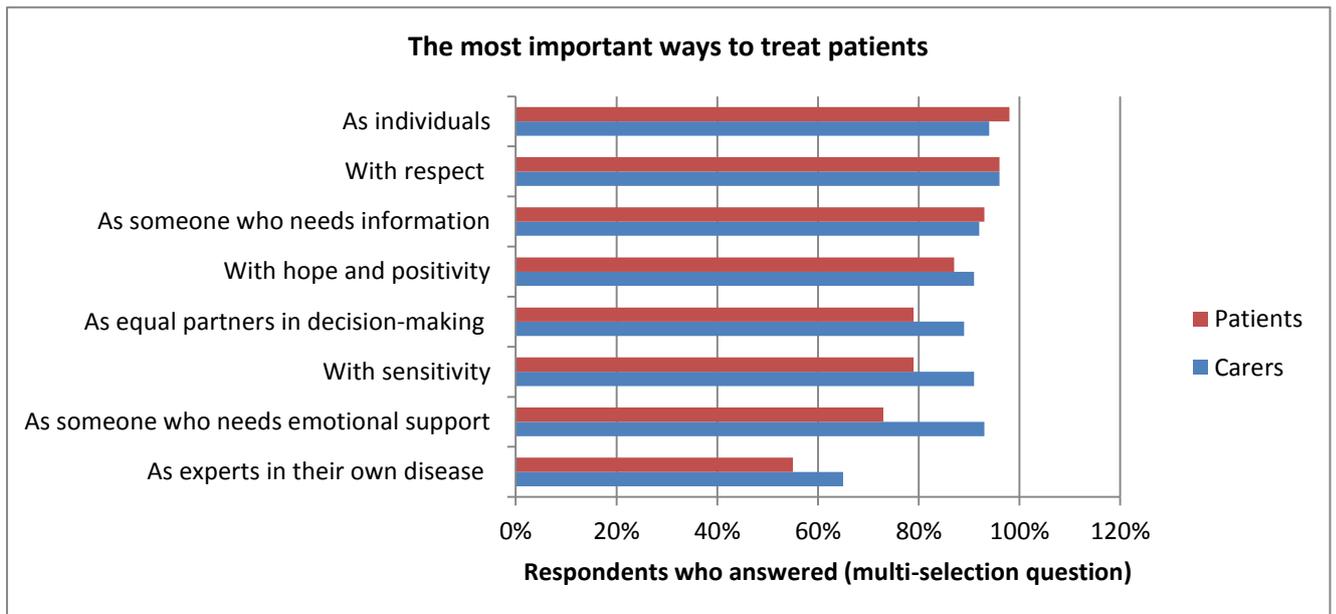
“A lung cancer nurse specialist would be good” and

“Important to have a co-ordinator to liaise between various doctors, surgeons, psychologists and nurses and follow the patient from the beginning of the disease”.



Treatment of patients – what is most important?

The top 4 ways identified for patients to be treated are: as individuals; with respect; as someone who needs information; and with hope and positivity – each of these options polled 80% or more by both patients and carers (see chart below). Carers however put a greater emphasis than patients on the requirement for emotional support; for patients to be treated as an equal partner in decision making and for patients to be treated with sensitivity.



Some comments expressed included:

“Gladly we were never treated as a statistic and always as individuals, both the patient and the family, and the care giving was customised around how we as a family functioned” and “is a need for professionals to more human, flexible and compassionate”.

Most difficult for patients when dealing with healthcare professionals

Most difficult for patients is to support the healthcare professional on shared agendas, e.g. write to hospital about resourcing issues (33%), followed by challenging healthcare professionals with their concerns (29%), followed by asking questions that seem silly or critical (21% of patients).

For all statements, carers expressed having a greater difficulty than patients with challenging healthcare professionals with their concerns (46%), followed by supporting the healthcare professional on shared agendas (40%) and asking questions that may seem silly or critical and telling the truth (both 34%).

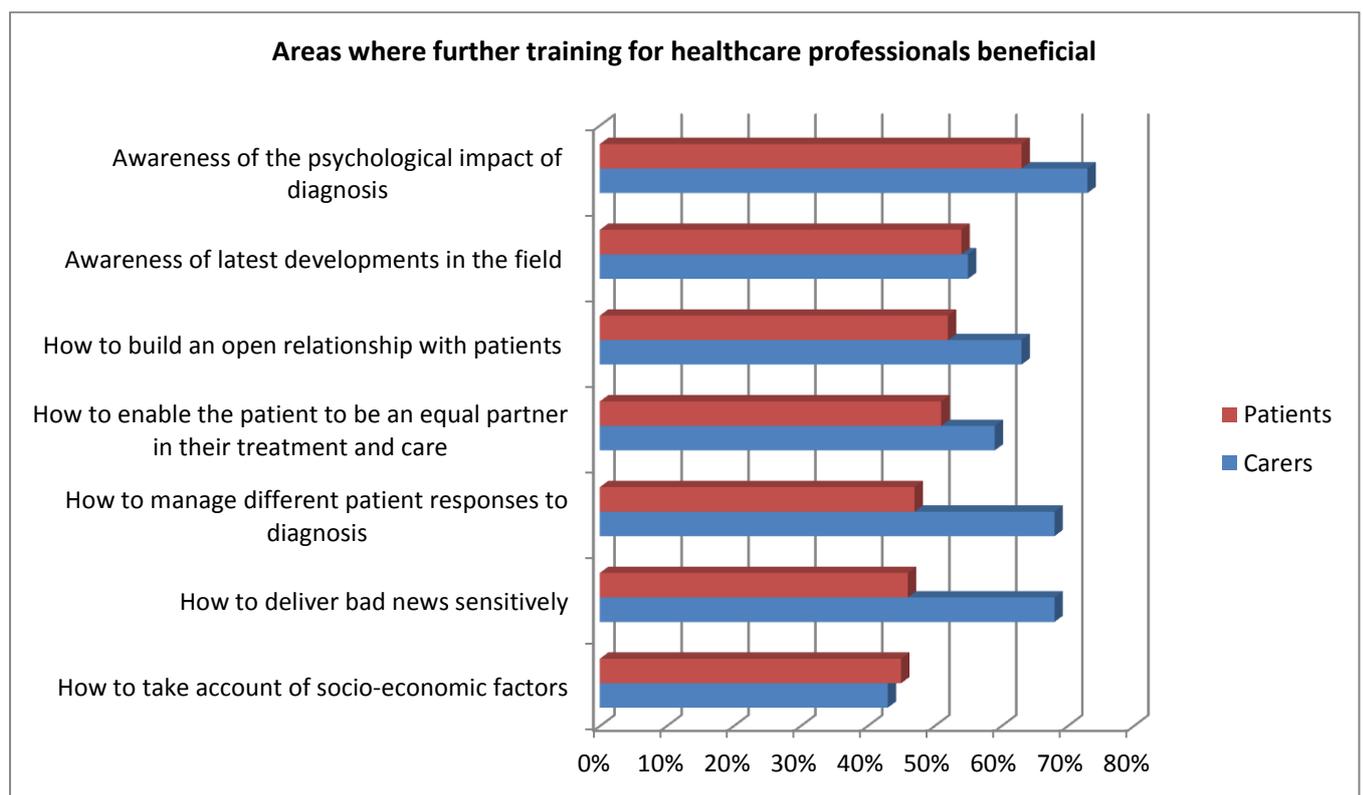
One respondent recognised that it depends very much on the personality and views of the healthcare professional and another that it depends on the patient.



TRAINING NEEDS

The questionnaire asked whether, from their own experience, the lead healthcare professional could have benefited from further training in a number of areas. There were four areas where over 50% of patients felt further training would be beneficial: Awareness of the psychological impact of diagnosis (63%), awareness of latest developments in the field (54%), how to build an open relationship with patients (52%) and how to enable the patient to be an equal partner in their treatment and care (51%).

For carers, six out of the seven areas were identified as requiring further training and all with higher percentage of individuals identifying than patients: Awareness of the psychological impact of diagnosis (73%), how to manage different patient responses to diagnosis (68%), how to deliver bad news sensitively (68%), how to build an open relationship with patients (63%), how to enable the patient to be an equal partner in their treatment and care (59%) and awareness of latest developments in the field (55%). The area that fewer respondents identified as requiring further training was how to take account of socio-economic factors – 45% of patients and 43% of carers.



Further comments on additional training were: *“standards in training vary greatly from one professional to another”* and *“socio-economic factors should not impact on treatment availability discussions”* and *“it is important that all healthcare professionals within the MDT are trained, professional and treat patients as people”* as well as *“No training can replace a human approach to patient”*.

d) Experiences of patients and carers

We asked respondents to share their good and bad experiences of treatment and care:

Good experiences

- *“It was a good experience dealing with professionals who always told the truth, admitted doubts or that they did not know how the disease would develop. We were offered two or three treatment options” (Carer, ES)*
- *“No negative experiences. My doctors have treated me as a partner. There remained no questions unanswered. That is how it should be” (Patient, DE)*
- *“Since I had had over 33 radiation treatments, the room was festooned with flags to celebrate that it was the last time. It was very touching” (Patient, DAN)*
- *“We had a very good relationship with the doctor – for information, care and a human relationship” (Carer, FR)*
- *“I found great people in the health service” (Patient, PL)*
- *“The hospital physician was always available for every need” (Carer, IT)*
- *“In all our experiences we found health professionals with good technical training, professional attitude and a willingness to be present whenever requested” (Carer, PT)*
- *“The doctor has always been direct with regard to diagnosis and therapy” (Carer, PT).*
- *“The initial message given was really bad, “You have lung cancer and we cannot cure you,” was the gist. But subsequent meetings were more planned and better implemented with good information. However, I would have liked to have contact with a good counsellor prior to or in connection with this” (Patient, SE)*

Bad experiences

- *“Not always available to paint the present and future outlook” (Patient, ES)*
- *“For me and my wife the experience was very bad when the oncologist told me that they would die. He had no sensitivity or empathy” (Carer, ES)*
- *“Often doctors state that it is the fault of the patient that they are sick” (Carer, PL)*
- *“Doctors should have the opportunity to talk with the patient / family privately; often such conversations take place immediately and in the corridor” (Carer, PL)*
- *“The approach of doctors and medical personnel was sometimes cold and devoid of interest in the individual. Patients tend to be treated as an object. There is no direct care of patients after treatment, this is seen as the responsibility of the patient.” (Carer, PL)*
- *“I felt thrown out to die without hope and that I was a problem to the professional” (Patient, ES)*
- *“The family doctor was not able to diagnose a pneumothorax and underestimated my symptoms saying it was stress”. (Patient, IT)*
- *“During biopsy by CT there was an oncologist present with medical students. When they saw my tumor, the oncologist said: “It seems that you have smoked a lot of cigarettes”. This is unacceptable from a doctor and I complained.” (Patient, NOR)*
- *“After diagnosis, there was no aftercare for example, a nurse. This should have been the case.” (Patient, NL)*

e) Stigma and campaigning

Several comments were made by respondents highlighting the stigma associated with a diagnosis of lung cancer and the importance of wider campaigning to develop greater awareness of the symptoms, and that it is not only a disease that affects smokers.

There were also some examples given of where healthcare professionals had made assumptions that lifestyle/blame could be attributed to the patient when this was not the case.

5. ERS International Congress workshop with patients and doctors, Sept 2015

Introduction

This second workshop brought together 10 members of the patient advisory group and 8 members of the ERS lung cancer working group to discuss in greater detail the patient experience and views around MDT working to help inform the development of a joint statement about lung cancer treatment and care across Europe.

Discussions

General comments

- Create a lay version of the MDT guidelines in different languages to be used by patients with the professional involved in their care.

Q: Make-up of MDT

- MDTs are very varied. You may have an oncologist, but they may be dealing with all kinds of cancers, or you may have one who is a specialist for lung cancer.

The make-up of an MDT has a big impact on the outcome of the care for the patient. Data from London shows that with less versus more expertise in lung cancer, there is a 20% versus 40% (respectively) 1-yr survival rate, in London. *[Professional, UK]*



- In German lung cancer centres, the structure and outcome quality of the MDT is well regulated. However, the process quality is not regulated. There are institutional psycho-oncologists in the centres. *[Professional, DE]*
- Primary care professionals are often not involved in MDTs and the information fed back to the local doctor and then to the patient loses a lot of detail. *[Patient, UK]*
- Frustration expressed about the system, where as a specialist he had worked quickly to get a diagnosis, but then the primary care giver who was to talk to the patient had said they would not give the patient their diagnosis until after a weekend. *[Professional, DE]*

- Patients have more impact on the government than doctors, so patients should demand more expertise on the MDT, as well as a wider spread of specialisms, e.g. psychologists as well as the cancer specialists. *[Professional, UK]*

Access to services and resources

- Equity of care can sometimes be a bad thing if a decision is made to remove useful services in order to be fair between regions. *[Patient, UK]*
- Bigger centres are often assumed to be better as they have more access to expertise. However, re-admission, after the first admission, will often be to a local hospital, not to a big central hospital in UK. *[Patient, UK]*
- A major problem in Germany is that if a patient goes to a small hospital they get treatment there, although they know the patient should be referred to a specialised centre. This is for reimbursement/financial reasons and should not be allowed. *[Patient, DE].*

In Germany they have recently adopted a National Cancer Plan and, as of 2018, lung cancer patients have to be treated in a specialist centre, and small/general hospitals are legally not allowed to treat lung cancer patients. *[Professional, DE]*

- In Poland, there is a lack of psychological support. The patients are left completely alone to deal with this side of their condition, and it is hard to find information too. *[Patient, PL]*
- Psychological support for patients is important at many points along the care pathway. For example, when returning to work, the fact that someone may need to keep their medical history secret could be a big problem. *[Patient, UK]*
- Access to molecular diagnostics and a comprehensive diagnosis is very important but this is very dependent on country, e.g. in Germany, 60% of patients do not get a comprehensive diagnosis. *[Patient, DE]*
- “Rapid clinics”, where MDT care means bringing all the healthcare professionals to a single clinic and the patients see them all in one day could be a useful model. *[Patient, UK]*
- Patients often get no choice of treatment. Some countries have no equivalent of the British General Practitioner, so there is no primary care access point for the patient - they have to deal with each specialist individually. *[Professional, UK]*



Patient-doctor communications

- Many patients hardly take in more than the bare facts of their diagnosis, then switch off from other details. The rollercoaster of emotions does not stop after diagnosis – it is often a long/hard path to reach acceptance. *[Carer, IRL]*
- Stress is a very big factor in having cancer. Felt she had both an illness and the feeling of being disempowered, and together this was very stressful. *[Patient, UK]*
- Patients are not adequately prepared to discuss details of their treatment with the specialists. They want to discuss but not necessarily all the details. *[Patient, PL]*
- Difficult to develop a good doctor-patient relationship as the doctor has no time and just a few minutes to see patient. *[Carer, ES]*
- A solution to the ‘time problem’ is that doctor should invest more time with the patient in the beginning (first meetings) to talk about diagnosis and prognosis. This will build trust and aid communication and ultimately save time in follow-up meetings. First 1-3 meetings are key. *[Professionals, DE/BE]*
- The first question should be “are you having any problems at the moment?” *[Patient, UK]*
- The doctor-patient discussion will be shortened further with implementation of MDT. MDT makes the communication part more redundant, (effect of doctor confirming a diagnosis and wanting to move onto the treatment part) and in that way is a step back in terms of doctor-patient communications. *[Professional, DE]*
- The importance of communication skills for doctors to improve outcomes is already there in research data but main problem is that it is not implemented. For example, the “SPIKES protocol” is a 6-step protocol for delivering bad news. We need to integrate this information/evidence so that it is applied. This is crucially also very dependent on cultural and regional differences (implementation needs to be adapted accordingly). Recommendations could be based on these differences in expectations (due to cultural /regional aspects). *[Professional, DE]*
- Structured and repeated training is needed for both junior and experienced clinicians. This needs to tackle the fear that the doctor has of the doctor-patient relationship, because it is linked to a situation emotionally affecting the doctor. Training needs to be face to face, with refresher courses repeated every 2 years. Communication skills training should be mandatory. *[Professional, DE]*
- The human element in the first consultation is very important and psychological skills awareness training should also be included. *[Patient, IT]*

Receiving information from MDT

- Diagnosis and treatment are the highest priority and for me that comes before respect and kindness. I am surprised that patients do not take the initiative and ask to be better informed. Patients from US by comparison are significantly more well-informed than European counterparts about options. *[Patient, DE]*
- Language is a barrier: more information needs to be available in languages other than English. *[Patients/Carer, DE, IT, ES]*
- Accessing research is difficult, e.g. published clinical trials are only accessible to researchers. *[Patient, DE]*
- No central doctor followed my journey and I saw 10 different types of doctors and sometimes received different information from different doctors. It was very confusing. *[Patient, IT]*
- Important to receive information in writing about your care and to be told the medical terms so you can look up more information; a short explanation from a doctor would be useful. *[Patient, UK]*
- The patient should receive an explanation (including hard copy) of explanations of the decision the doctor took to arrive at the treatment decision. This would personalise it, be cost effective and save time. Some patients do not want to know this, but a patient should have the choice to receive this information. *[Patient, UK]*
- The outcome of MDT meetings is usually given verbally to patients, and only the final agreement is given, not all the discussion points. *[Professional, UK]*
- Would like patients to receive a hard copy of exactly what tumour type diagnosis they have. *[Patient, UK]*
- Direct the patient towards quality sources of information. *[Carer, IRL]*
- Information for patients should be positive not just “doom and gloom.” *[Patient, UK]*



Patient choices in decision making

- Are great differences in what information patients want and how much they want to be involved. *[Carer, IRL]*
- The lung cancer field could learn from how patients are involved in the mental health system in the UK. *[Patient, UK]*
- Are generational differences in whether people want to be involved in their care, older generations may not have questioned the doctor's decisions, whereas younger patients want to be involved in the decisions about their care. *[Patient, UK]*
- Helpful to steer patient towards a sensible "best" decision with a motivational interview. *[Carer, IRL]*
- In Germany, patients are given choices based on the risks involved. *[Professional, DE]*
- The cultural, educational and economic status of a patient is important in their care. *[Carer, IRL]*
- Classifying people by socioeconomic status is not helpful as people move to areas thought of as "well-off" or "deprived" but may not themselves be in these groups. People also educate themselves to change groups. *[Patient, UK]*
- Treatment is not always presented as a patient choice, e.g. was told I could not have an operation for my cancer, but no explanation was given. I had been offered radiotherapy but in the tone that it was a second-choice treatment. I felt patronised and disempowered. *[Patient, UK]*
- Patient should get information of all available options. In Germany doctors are reluctant to provide this. Most likely I would have been dead by now had I not investigated myself. *[Patient, DE]*

Plenary discussion

Q: Do patients expect holistic care e.g. spiritual?

- Lung cancer nurses would have more general holistic capabilities, but individual needs were important e.g. not all patients need spiritual care. *[Professional, DE]*
- Important to develop a patient-centred approach, e.g. ask if patient has spiritual needs – caution against one-size fits all approach for MDT statement. *[Patient organisation representative, UK]*
- There are no social workers any more in lung cancer care in UK. *[Patient, UK]*



Q: Would sending patients a questionnaire ahead of their appointment be helpful?

- Time is often limited in a face-to-face discussion with patient, and if there were particular boxes ticked on a questionnaire, that would help the doctor to focus on particular aspects of care that might be useful for the individual. Is aware that patients would prefer lengthier conversations, but this is not always possible. *[Professional, DE]*
- Examples of patient questions for doctor to take to MDT conference: what is important to the patient, what is their family setting, work situation etc. *[Professional, DE]*
- In UK, a questionnaire is available for doctors to use, to find out about patients' needs in holistic sense. *[Professional, UK]*
- Could ask how often the patients wanted their other (psychological, spiritual) needs assessed, i.e. how often the questionnaire would be sent? *[Professional, UK]*. Discussion on this suggested that the answer to this would vary along the path of the disease. *[Patients, IT, DE, UK]*
- Sending a questionnaire would raise questions in a patient's mind that might otherwise not have been. Worried that excess information would be generated in such an advance questionnaire, and no further action would be possible. Make sure that if questions were asked, the answers were put to good use. *[Patient, UK]*
- Important not to wait until a patient asks for psychological support. The support should begin at the start of the care process, and be a normal part of the

process. Stressed that is important that the support is offered optionally as some patients would be offended by the offer of a psychologist and that it implied they were not coping. *[Patient, IT]*

- A partnership approach is important, and conversations are far more preferable to paper questionnaires. *[Patient, PL]*

Q: What other information do patients think the MDT conference should know about them (apart from the details of their cancer stage)?

- Side-effects have very different impacts on the lives of individuals, i.e. how important or how much effect they would have was very varied. Stressed that for some people, lengthening their life by 3 months would not be worth it if side-effects were too great. *[Professional, DE]*
- Agreed that asking a patient about whether quantity or quality of life was more important to them, was a really critical question. *[Patient, PL]*
- What is most important to the patient including personal feelings for example, do they want psychological support or do they talk to their friends.
- Being offered a choice of time of day for appointments important. Being sent an appointment time in the post with no chance to choose not a good option. Ask whether morning/afternoon/evening slots would be best. *[Patient, UK]*. In Poland, they do get asked a question about appointment timings. *[Patient, PL]*
- An important question to ask is about family history. Experience of being far more frightened about the diagnosis of cancer in oneself after having already seen a close family member die of lung cancer. She also thought that re-diagnosis (after an initial cancer had been cured) was different from the initial diagnosis, in terms of psychological impact. *[Patient, UK]*
- Doctors can deal with people who say what they want. Important to remember the people who do not say much, who are more passive; it was often hard to find out whether they really wanted a treatment that was offered. He had experience of difficulties with family members who wanted different things from the patient themselves, who might for example be forcing a patient to have treatment they would rather not have. *[Professional, DE]*

Next steps

The projects' next steps are to finalise and complete the following in 2016:

- Launch of the patient priorities - lung cancer website.
- Publication of a joint statement on MDT working to be published in a European journal for healthcare professionals.
- Feasibility of developing a European Patient Charter for Lung Cancer based on the priorities identified through this project.
- Evaluation of the project to inform future patient-led projects.
- Maintaining the patient advisory group to continue to provide their expertise and perspectives to lung cancer activities within ELF and ERS.