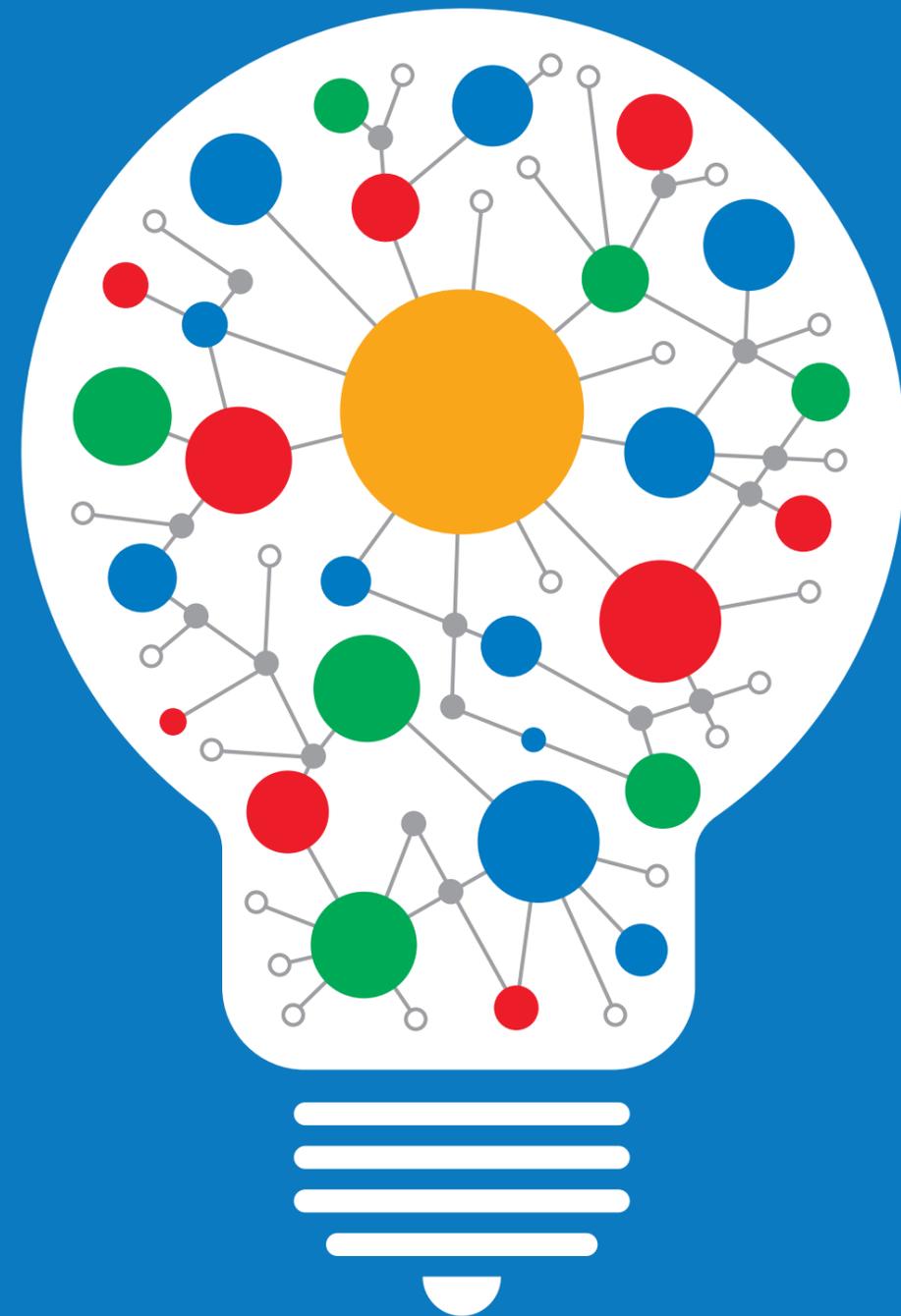


# Informing Patients, Improving Outcomes: Optimising information sharing in lung cancer

*World Cancer Congress 2016  
Lounge Session Report*





## About this Report

This report has been commissioned by **Boehringer Ingelheim**, with insights and contributions from:

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This report summarises presentations and discussions from a Lounge Session entitled '**Informing Patients, Improving Outcomes: Optimising information sharing in lung cancer**' which took place during the **World Cancer Congress (WCC)** in December 2016.

The Congress is a biennial meeting organised by the **Union for International Cancer Control (UICC)** and the Lounge Session was supported by **Boehringer Ingelheim**.



Foreword by  
**Professor Dame Lesley Fallowfield**



There were **1,825,000** new cases of lung cancer diagnosed in 2012 globally<sup>1</sup> resulting in many patient-doctor conversations about the symptoms, prognosis and treatment of lung cancer. Lung cancer is not just one disease and consequently there are many different types of treatment for each specific type of lung cancer.

Regardless of where a patient lives and whatever their type of lung cancer, they should have access to good quality, evidence-based information so they can understand their condition and can take an active part in decisions about their treatment.

The amount of information available to patients is increasing, largely due to the internet. However, the quality of this information can vary so it is very important that healthcare professionals can direct patients to qualified sources of good quality consumer health information, including health related websites.

As a healthcare professional, I have noticed that patients are becoming increasingly interested in participating in clinical decisions and taking responsibility for their own health, reaching out for more detailed information about therapeutic intent of treatment. As testing for particular types of lung cancer treatment becomes more readily available, patients are beginning to demand a more personalised therapy choice.

A group of oncology professionals met at **World Cancer Congress (WCC)** to discuss the role of patient organisations, doctors and pharmaceutical companies in providing relevant information for patients with lung cancer to help them be more involved with their own cancer journey.

**This report summarises the meeting, assesses the difficulties regarding the provision of information to patients and the communication barriers and challenges that may exist.**

## Lung cancer patient information

To be faced with the diagnosis of a life threatening disease, like lung cancer, can understandably be incredibly hard. The historic and strong association of lung cancer with tobacco means that there is a notable stigma and negativity associated with lung cancer. Some patients can therefore be reluctant to actually engage with their healthcare professionals, due to associated emotional turmoil. Getting complex information across to patients with lung cancer can sometimes be very difficult.

**Patient organisations (POs)** have an increasingly important role in supporting patients and can often be the driving force in empowering patients to take an active part in their care. The platform of information sharing on social media networks can provide POs with the opportunity to interact with individual patients and deliver the particular information they need.

It can be challenging for POs to keep up-to-date with the ever changing clinical landscape of new data and evolving treatments. Cross-dialogue between POs and the medical community can help to ensure POs understand the fast-moving treatment landscape, ensuring the information they then share with patients is as accurate and balanced as possible.

*“Doctors are expecting that patient organisations will have a much greater influence on patient decision making in the future.”*

Professor Pierre Fumoleau ,  
Centre Georges François  
Leclerc, France

*“We know that patients who understand what their treatment is are much more likely to be compliant. We know that if they anticipate side-effects and what to do with them, they are going to have a better outcome. And we also know that if they know what to anticipate, they are less likely to have potential complications. So there are important reasons why patients need to be well-informed.”*

Dr Jesme Fox,  
Global Lung Cancer  
Coalition



## Doctor-patient communication

The prognosis for lung cancer is poor; every **30** seconds, someone, somewhere in the world dies of lung cancer and only **1 in every 10** people with lung cancer is alive **5** years after diagnosis.<sup>2</sup> Doctors need to communicate this poor prognosis, without taking away hope from the patient.

Over the last decade significant work has been carried out to understand the genetics, genomics and the underlying molecular biology of cancer which has facilitated some major therapeutic advances. Lung cancer is not simple to explain. It is a multitude of different diseases which has resulted in more targeted treatment for patients.

*“It is important that a health professional understands and knows how to communicate bad news to a patient, and that there is always something they can do to help.”*

Dr Jesme Fox,  
Global Lung Cancer  
Coalition,

*“As doctors, we have got to make sure that the information we are giving is communicated professionally yet with empathy. We have got to make sure that it is evidence-based, that it is accurate and also patients can understand it.”*

Professor Ian Olver,  
Sansom Institute for Health  
Research, Australia

*“These advances in clinical practice are so rapid that no single clinician or practitioner could possibly keep up with it all. There is a lot a doctor needs to synthesise to start with, then simplify it even further to help guide the patients.”*

Professor Ian Olver,  
Sansom Institute for Health  
Research, Australia

## Addressing patient needs

Following a diagnosis of lung cancer, patients enter an unfamiliar new world involving medical language that they have probably never heard of before. In addition to lung cancer symptoms, patients may also need to come to terms with new side-effects caused by their treatment.

Often, there is not a simple explanation and it is hard for patients to understand exactly what is happening to their body. Therefore some patients may look on the internet to find more information rather than asking their doctor, but are often faced with information or statistics that can be inaccurate and hard to digest.

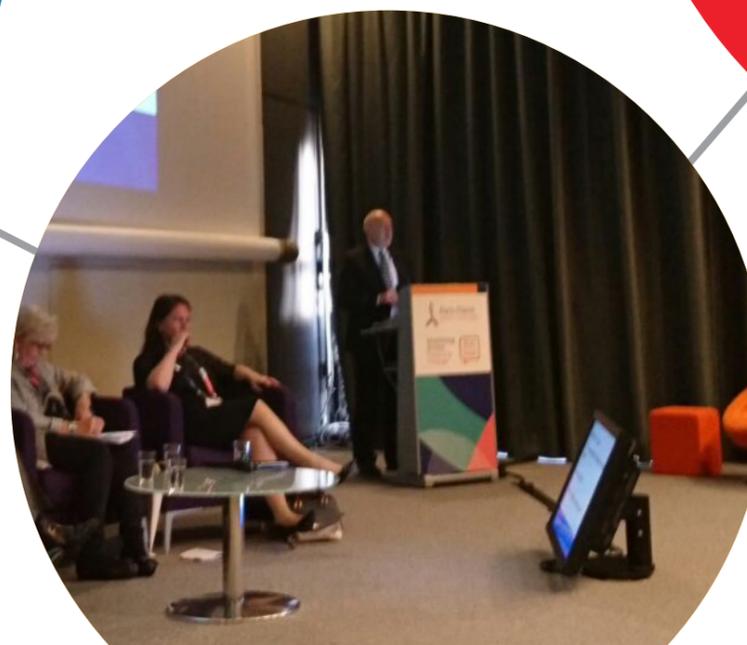
As lung cancer is more common in patients over 65, doctors often find that patients would like to have the information about the disease and their treatment on a leaflet or a brochure to take home with them. Therefore accurate advice needs to be available to patients in a range of resources.

*“Patients almost need an undergraduate degree to have a fighting chance of understanding what is wrong and the different treatment programmes available.”*

Professor Dame  
Lesley Fallowfield,  
Professor of  
Psycho-oncology

*“Now with the increasing therapeutic options for the different types of lung cancer we can test for, it is hard for a patients to understand what they are being offered and it can be difficult to know the difference between the treatment choices. It is just much more complex.”*

Professor Ian Olver,  
Sansom Institute for Health  
Research, Australia



## Information sharing: from clinical development to disease education

There is a wide range and crowded marketplace for cancer information, including traditional media, newspapers, magazines, TV, radio and increasingly through social media and the internet. After the initial conversation with a doctor, patients will often go home and use the internet to find out more about their disease and perhaps ask the questions they were too afraid, or forgot, to ask their doctor.

Professor Ian Olver shared some typical questions that his patients have asked him when diagnosed with lung cancer:

*What type of lung cancer do I have?*

*Can I be tested to get a specific type?*

*Are there newer treatments available?*

*How will my daily life be affected?*

*Will treatment affect my fertility?*

*Should I consider participating in a clinical trial?*

However many websites contain information that is inaccurate or unhelpful, which may cause further confusion. A 'well-informed' patient doesn't necessarily mean a 'well-educated' one. If they have read a lot on the topic, it can sometimes make it harder for healthcare professionals to provide recommendations to patients as they may have already formed their own opinions.

Getting involved right from the beginning of the treatment pathway helps a patient truly understand the physician's therapy goals for them. Physicians can also inform patients about available clinical trials they could participate in.

***“Having well-educated patients does make a difference. If patients are involved with the doctor in the joint decision-making, they are more likely to get the best treatment for them. Also, doctors who use patient reported outcome measures will help to shape and improve care delivery for future patients.”***

Professor Pierre Fumoleau,  
Centre Georges François  
Leclerc, France

***“As a doctor you give information, but you also receive information from the patients, because once a drug is marketed, this is not the end of the drug life, this is the beginning of the drug life, and you have to learn about safety and how the drug performs in real life.”***

Professor Pascal Piedbois,  
Boehringer Ingelheim

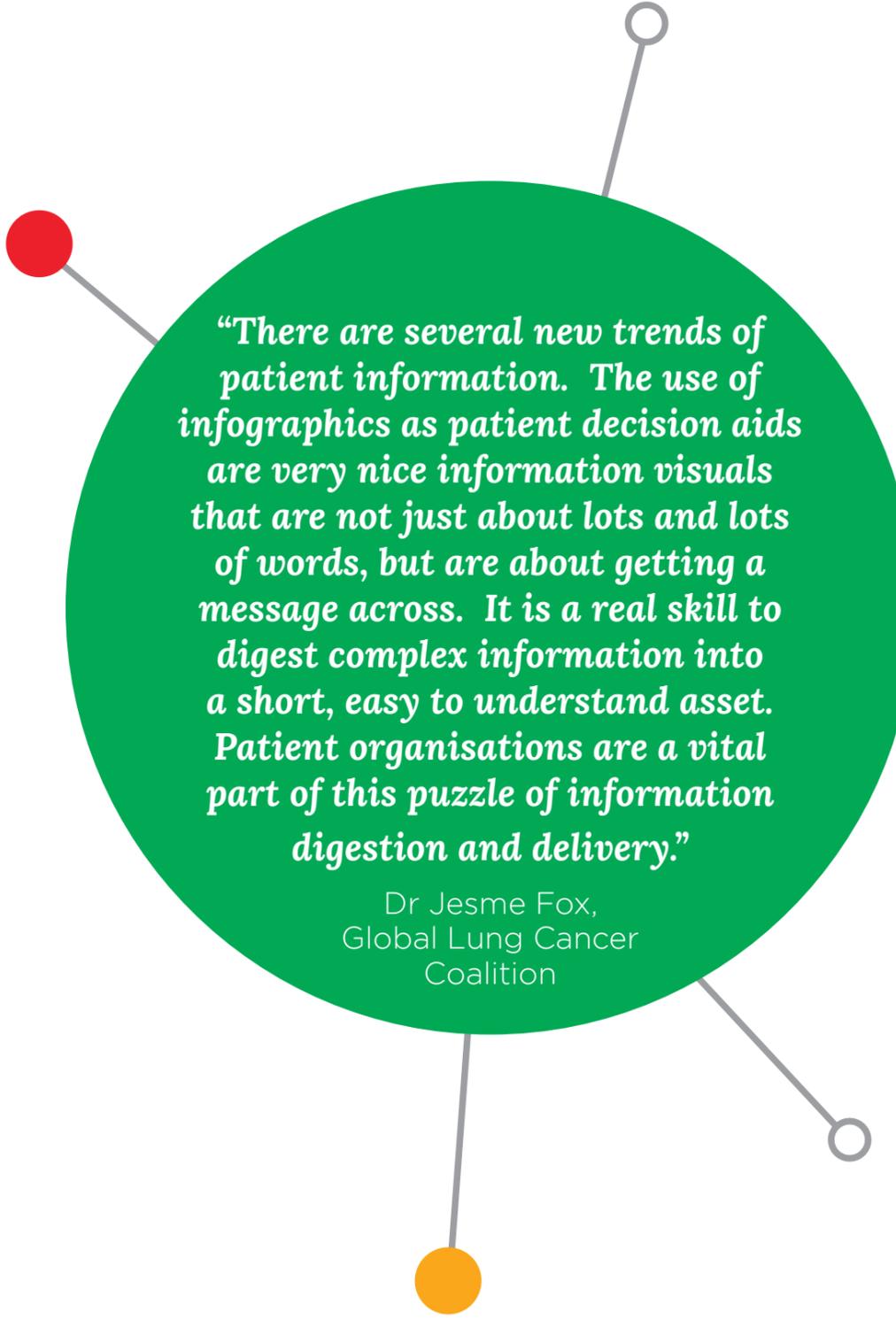
## Call to action

As a summary of the discussion points in this report, **four** areas have been identified to help optimise the information that is shared between patients, healthcare professionals and patient associations and to help combat the communication barriers that exist.

### 1

## Providing simple accurate information

- Patients need clearer guidance on what information they should be relying on. Simple and accurate information that is provided at the first consultation with a doctor, or interaction with a patient association, could help prevent the overload of information and the misinformation they find on the internet
- Professor Ian Olver suggests that a list of prompt questions, which a patient can print out prior to their appointment, could be a technique for improving the communication patients have with their doctors. There is a huge spectrum of questions that patients need to ask, not just about the treatment and the outcome of the disease but also about their lifestyle. Having a prompt list will prevent forgetting to ask something, while also trying to take on the information the doctor is providing



*“There are several new trends of patient information. The use of infographics as patient decision aids are very nice information visuals that are not just about lots and lots of words, but are about getting a message across. It is a real skill to digest complex information into a short, easy to understand asset. Patient organisations are a vital part of this puzzle of information digestion and delivery.”*

Dr Jesme Fox,  
Global Lung Cancer  
Coalition

## 2

### Keeping up-to-date with technology

- As the world in which information is shared continues to change, so does the way the patient organisations need to communicate information. Mobile apps are becoming useful resources for patients and, as technology improves, the delivery of accurate and relevant information, including tips on how to get the most from their doctor consultations, can be delivered directly to patients
- There is a requirement for doctors and patient organisations to ensure the delivery of information is accurate, easy to understand and available via appropriate channels

### 3 Making data meaningful

- Patient organisations can act as a conduit between scientific research and patients in order to translate complicated data into something meaningful and understandable for patients
- As patients become more involved in their cancer journey, communication of clinical trial results, helps to provide the patients with the rationale required to understand / accept a particular treatment choice

*“When you talk to a patient, you have to consider patient perspectives. Here at Boehringer Ingelheim, we are working on lay summaries to make sure that the way we report the results makes sense, which I think is most important for the patients.”*

Professor Pascal Piedbois,  
Boehringer Ingelheim

### 4 Working together

- To aid patient education, HCPs and POs should work together to ensure patients are not only informed but understand their disease and treatment pathway
- HCPs and POs can work together, by sharing and highlighting best practice, to encourage patients to become more confident and active decisionmakers
- There is an opportunity for the pharmaceutical industry to collaborate with POs and HCPs to help achieve common objectives such as improving patient information. Continuous insights and learnings from research and development can help provide the way forward to advance clinical practice in lung cancer

*“We can only ensure highly informed lung cancer patients, if we all work together”*

Professor Pascal Piedbois,  
Boehringer Ingelheim

## Disclaimer

Boehringer Ingelheim sponsored the Lounge Session at the World Cancer Congress (WCC) and the development of this report. Boehringer Ingelheim strive to continue to bring key stakeholders together, raise public awareness of lung cancer, and support clinicians in delivering high-quality lung cancer care.

1. <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer/incidence#heading-Two>
2. <http://www.lungcancercoalition.org/lung-cancer-facts.html>