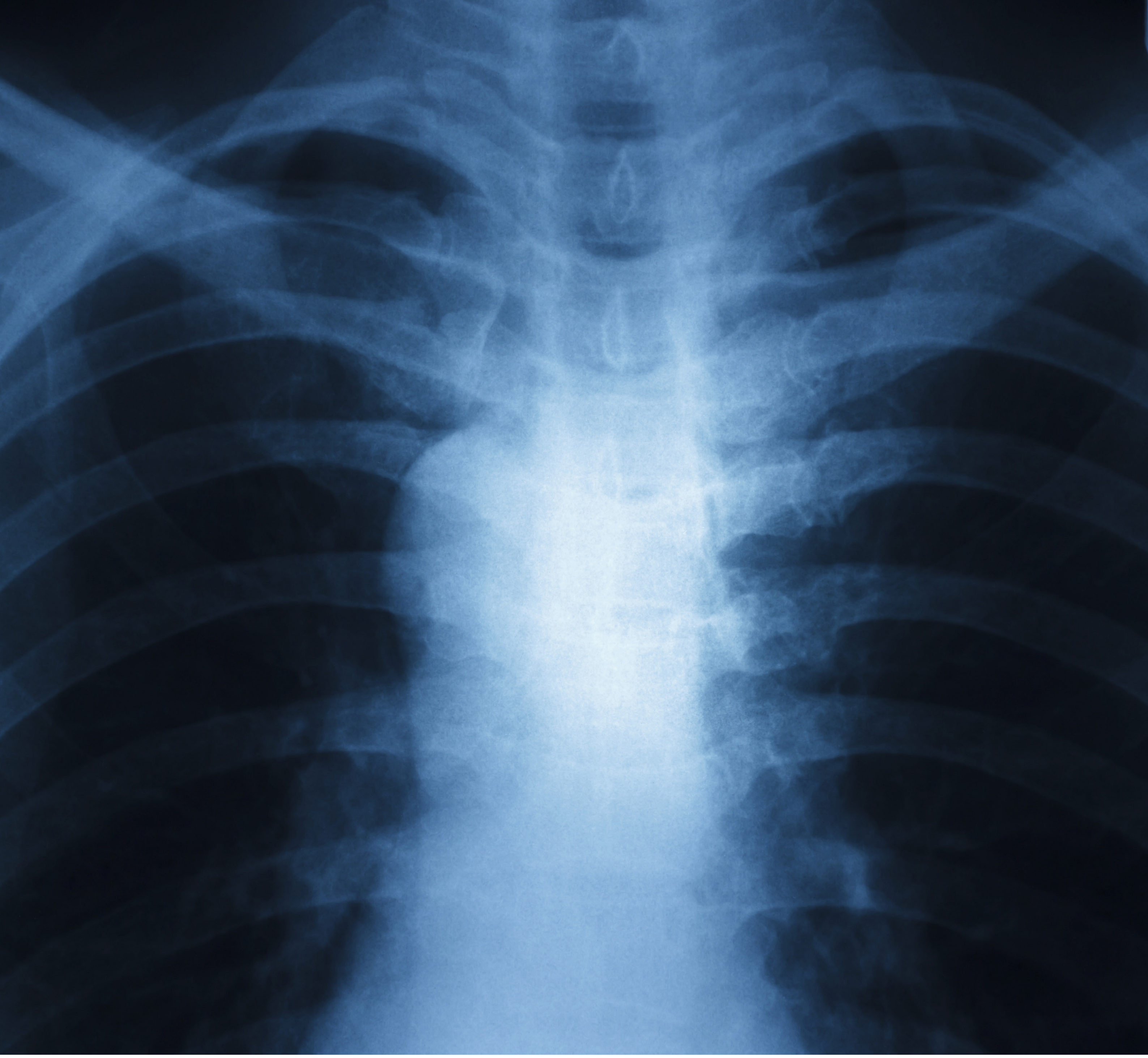


Connected Solutions for Improved Health and Wellbeing in COPD

Report authors:
Ana Maria Arboleda

Clare Moloney

Professor John Weinman

ATLANTIS HEALTHCARE
PatientResearch™
Summarized

Meet the experts

The Authors

Ana Maria Arboleda, Managing Director, Atlantis Healthcare, Spain

Ana Maria has more than 20 years' experience in Relationship Marketing, with extensive expertise in designing and implementing patient support programmes involving all the stakeholders in the patient circle of care across chronic and acute diseases. She understands the main issues for the pharma industry, patients and healthcare professionals (HCPs) in the Spanish environment. Prior to joining Atlantis in 2010, Ana Maria worked as a consultant with international groups in consumer loyalty for the business-to-consumer and business-to-business environment. Ana Maria brings extensive experience in managing complex projects and teams in multicultural environments, having worked in the Americas and Europe. She has an MBA and a degree in Communications Science majoring in Marketing and Advertising, and is fluent in French, English and Spanish.

in http://es.linkedin.com/in/anamariaarboleda/en

Clare Maloney, Senior Health Psychology Specialist, Atlantis Healthcare, UK

Clare has an MSc in Health Psychology and is currently working towards her Doctorate in Health Psychology (University of the West of England) investigating illness perceptions and health behaviour change in patients with intellectual disabilities. She has developed behaviour change interventions across a range of disease areas including psoriasis, COPD, acute coronary syndromes, atrial fibrillation and depression. Other research interests include telecare and telehealth, the link between emotional wellbeing and health, and the role of music therapy within medicine.

in http://uk.linkedin.com/pub/clare-moloney/33/681/2b9/en

Professor John Weinman, Professor of Psychology as applied to Medicine at the Institute of Psychiatry, King's College London, and Head of Health Psychology at Atlantis Healthcare UK

Professor John Weinman is Head of Health Psychology at Atlantis Healthcare. He is recognised as one of the founders of modern health psychology, and his main research areas include cognition and health, communication and decision-making in healthcare, and self-regulation and self-management in chronic illness. Professor Weinman has published dozens of papers, and written and edited several textbooks. He is the founding editor of the medical journal *Psychology and Health* and set up the UK's first Master's programme in health psychology.

in http://uk.linkedin.com/pub/john-weinman/48/845/811

Contributors

María Fortún, Lead Health Psychologist Specialist, Atlantis Healthcare, Spain

in http://es.linkedin.com/pub/maría-fortún-sánchez-phd/40/383/a48/es

Linda Thompson,CEO, Asthma Auckland, Executive Director, Asthma NZ, Editor, O₂ Journal of Respiratory Health

in http://nz.linkedin.com/pub/linda-thompson/17/234/628/en

Jared Poppelbaum, Director, Population Health, Atlantis Healthcare, New Zealand

in http://linkd.in/1uhWpdN

Janet Delooze, Nurse Educator, Astham New Zealand

Executive summary

Chronic obstructive pulmonary disease (COPD) is a progressive and debilitating disorder, which, as it progresses, places a significant burden on individuals and those caring for them. This is not only in terms of dealing with the condition itself but also in adhering to disease and treatment self-management programmes, which are integral to promoting better outcomes, both clinically and psychologically, for these individuals. In addition to improving individual outcomes, there are significant implications for broader healthcare systems in terms of reducing the number of hospital admissions and downstream costs of care.

Behavioural-change interventions provide an opportunity to move beyond the 'simple' provision of information and instead work with patients, caregivers and others involved in their care to provide tailored, evidence-based support that will promote optimal outcomes. Interventions that draw on core behavioural and psychological theories and frameworks have proven to be more successful in driving these changes, both in the short term and over time.

The aim of this report is to explore some of the key psychological theories and principles that underpin innovative wellness strategies, with a focus on the real-world challenges faced by people managing their COPD, in order to highlight key opportunities to *improve patient support and define connected solutions* that address the unmet needs of these patients.

In this White Paper report you will learn more about:

- Complex challenges faced by patients in managing their COPD
- ***Levanthal's*** *common sense approach to health and illness*
- Application of the capability, opportunity and motivation (***COM-B***) *model to adherence and behaviour change interventions*
- Understand the real reasons ***'why'*** patients are non-adherent
- ***Opportunities to better support COPD patients*** and achieve optimum health outcomes

Changing the mindset of patients can help with self-blame and changing HCP mindset is key to avoiding unnecessary stigma **#rwCOPD**

Introduction

Chronic obstructive pulmonary disease (COPD) is a common and preventable lung condition characterised by persistent airflow limitation. The diagnosis comprises a combination of small airways disease (obstructive bronchiolitis) and emphysema (parenchymal destruction), both of which are caused by lung damage from long-term inhalation of noxious agents such as those contained within cigarette smoke.

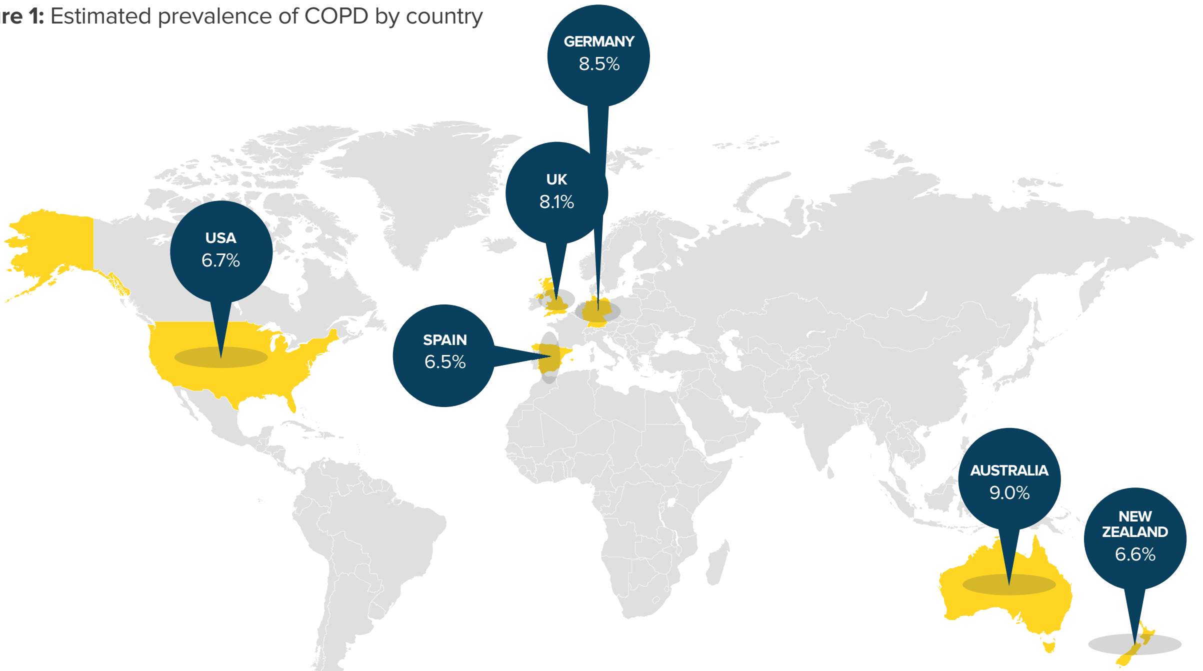
Its treatment is associated with non-adherence rates of around 50%[1] despite the fact that appropriate use of medication has been shown to reduce the risk of death by 60% and of hospitalisation by 42%.[2] This is because effective self-management, which includes adherence to not only medication but also greater physical activity, has been shown to slow down progression of the disease, leading to reduced hospitalisation rates and lower COPD healthcare costs. But for patients to effectively self-manage, they need to feel confident that there are things they can do and to be supported in that by all healthcare professionals (HCPs) they come into contact with.

In the absence of treatment the condition gradually progresses via chronic inflammation in the airways and lungs that causes structural changes and narrowing of the small arteries. Symptoms such as breathlessness (dyspnoea), a persistent cough and sputum production gradually increase in severity to restrict even simple tasks such as walking up a short flight of stairs or carrying a suitcase. People living with COPD can also expect to experience sudden exacerbations of their condition when they contract an infection, which often leads to hospitalisation, accounting for the greatest proportion of COPD healthcare costs.

Prevalence of COPD

COPD is described by the COPD Foundation as the third leading cause of death in most countries [after heart disease and cancer] and one that 'universally receives disproportionately low levels of care, research funding and general awareness'.[3] According to the World Health Organisation, 210 million people had COPD in 2008 and its burden in terms of disability-adjusted life years is ranked tenth worldwide.[4] There is wide consensus that COPD is a growing global health issue as people live longer. The Continuing to Confront COPD study, conducted by GlaxoSmithKline (GSK) on more than 4,000 patients from 12 countries between November 2012 and May 2013, found prevalence rates ranging from 7% to 12%, which are generally higher among men than women and consistently rise with age (see Figure 1).[5]

Figure 1: Estimated prevalence of COPD by country



Country	Prevalence (based on diagnosis)	Prevalence (based on GOLD criteria)	Hospitalisation rate (per 100,000 people)[11]
Australia	9%[6]	14%[6]	312
Germany	8.5%[5]	13.2%[8]	201
New Zealand	6.6%[7]	14.2%[7]	319
Spain	6.5%[5]	10.2%[9]	139
UK	8.1 %[5]	Not available	213
USA	6.7%[5]	10.2 - 20.9%[10]	230

Global Spotlight

AUSTRALIA

COPD is the fourth leading cause of death and disease burden in Australia, after heart disease, stroke and cancer,[12] with prevalence estimated to be approximately one in seven Australians over 40.[13] It is the second most common cause of avoidable hospital admissions.[14]
In 2008, the financial cost of COPD was estimated to be A$8.8 billion, with a further cost of A$89.4 billion attributable to overall value of loss of wellbeing. The direct annual cost to the Australian healthcare system is estimated to be A$857 million – more than half of which relates to hospital care. The estimated annual cost of treating a person with COPD is A$724.[15].

GERMANY

A total of 6.8 million people in Germany suffer from COPD. Every eighth affected person is over 40 years' of age.[16]

Approximately 3.1 million persons are unable to work due to COPD – with 10,000 of them being forced into early retirement.[17]

GERMANY (cont.)

In terms of the number of days spent in hospital, COPD is one of the main causes of disease in Germany, alongside lung cancer and pneumonia.[18]

The total cost to the German health system is €4.5 billion in direct costs and €3.94 billion in indirect costs,[19] whereby the annual cost per COPD-patient is estimated at between €1,210 and €3,490 depending on the severity of the disease.[20]

NEW ZEALAND

COPD is estimated to affect 15% of New Zealanders over the age of 45 and is the fourth leading cause of death after cancer, heart disease and stroke.[21] It also represents one of the most significant healthcare disparities in the country, with Māori people being more than five times more likely to die from COPD-related causes than non-Māori, as well as being affected by COPD up to 20 years earlier.[22]

SPAIN

In Spain, COPD is the fifth leading cause of death among males, with an annual rate of 61 deaths per 100,000 populations; and the seventh for women, with an annual rate of 20 deaths per 100,000 (in 2005). The rate of annual mortality increases significantly by age group[23].

The EPI-SCAN study (n= 3,824) showed that COPD affected at least 10.2% (IC95%9,2–11,1) of people between 40–80 years old.[24]

In Spain, the impact of COPD on the National Health System is considerable.

In 2005, *"Encuesta de Morbilidad Hospitalaria"* (Hospital Morbidity Survey) indicated that COPD was responsible for 9.3% of all hospital discharges for respiratory diseases in women and 28.2% among men (the main cause of hospital discharge for respiratory disease in the group between 55 and 89 years).[25]

Besides posing a great burden in terms of premature death and disability, COPD has a significant impact in terms of economic costs and quality of life in patients with COPD and their families.

SPAIN (cont.)

The costs range between 675–775 €million per year in 1994 for Spain, including the direct and indirect costs.[25]

UK

COPD is the UK's fifth biggest killer disease[26], claiming more lives than breast, bowel or prostate cancer; it is the second most common cause of emergency admission to hospital[26] and one of the most costly inpatient conditions treated by the National Health Service (NHS). It is estimated that the direct cost of providing care in the NHS for people with COPD is almost £500 million a year[27] – more than half of which relates to hospital care.

The estimated annual cost of treating people with mild COPD is £149; it is £1,307 for a person with severe COPD.[27] Proper self-management of the condition can reduce hospitalisation by up to 42% and risk of death by as much as 60%.

USA

In the USA, nearly 13 million adults are estimated to have COPD.[28] The disease claimed the lives of more than 140,000 adults in 2010, falling only behind heart disease and cancer.[29] Close to 24 million adults have evidence of impaired lung function, indicating an under–diagnosis of the disease.

While historically, COPD impacts more men than women, the number of diagnosed females is rapidly increasing and 2014 was the 11th consecutive year in which women have exceeded men in COPD-attributed deaths.[29] Traditional health disparities, including socioeconomic factors, also impact this population. Despite the fact that COPD is under-diagnosed in the US, its economic burden is substantial. Estimated costs were projected to be nearly $50 billion in 2010, including $29.5 billion in direct healthcare expenditures plus $20.4 billion in indirect costs related primarily to complications and cost of care, hospitalisation and soaring ambulatory/oxygenation expenses.[30]

Unmet needs of people with COPD

As mentioned, self-management, including medicines adherence, is a key part of managing COPD, and when achieved can help to bring about:

- **Better symptom control**
- **Prevention of exacerbations**
- **Slowing and possible prevention of disease progression**
- **Reduction of disease-related mortality**

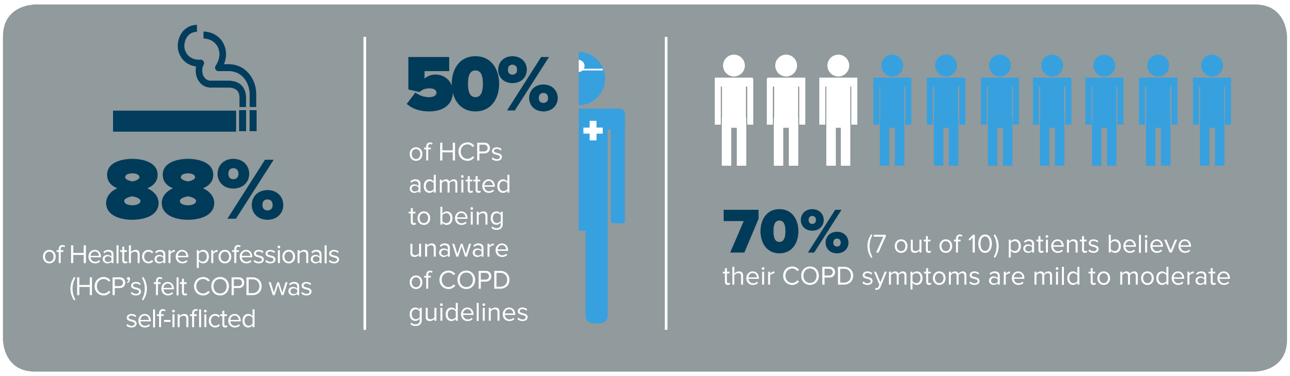
However, research shows that there are a number of unmet needs that people with COPD face, impacting on their ability to optimally self-manage. These needs are reflected in a recent *Atlantis- sponsored* social–media analysis looking at the unmet needs of COPD patients. Key findings of the report included *quality of life* as the main topic of conversation, with patients seeking advice and information on *treatment options and managing symptoms*, as well as seeking out advice on *smoking cessation* – ranging from helpful resources to quit and shared experiences from other people in their position. Increased online connectivity and shared experiences with peers via COPD patient forums allows patients to feel more empowered, and improved support through a range of high–value educational and lifestyle information can be enormously helpful in some instances.

Public awareness campaigns can also help combat ignorance that the condition exists at all, one of the main findings of an International COPD Coalition (ICC) survey into the unmet needs of COPD patients.[31] This found that, in most of the 29 countries surveyed, awareness among the general population was less than 10%. Increasing public awareness of the condition can help to build the social support available to individuals with the condition and enhance their wellbeing through helping them to feel that their situation is better understood.

> **“Both patient and physician surveys demonstrated continued confusion about the diagnosis of COPD and treatment choices.”**

There are opportunities for healthcare organisations to help increase awareness of the condition, including the provision of information on how to *better control symptoms* by explaining that breathlessness is not simply a by-product of ageing and or factors such as smoking but sign of a *progressive disease* that can be significantly helped with medication and lifestyle change.

And this approach can go some way to challenging the prejudice that has traditionally surrounded the disease. A COPD Resource Needs Assessment Survey, conducted in 2004, questioned more than 1,000 patients, 500 primary care physicians and 500 pulmonologists in the USA for their views. Among the physicians, 88% felt COPD was self-inflicted and more than a third were negative about the treatment of patients, particularly if they continued to smoke. Patients were generally uninformed about COPD and 50% of primary care physicians admitted they were unaware of COPD guidelines. The COPD Foundation, which was founded that year, said, “Both patient and physician surveys demonstrated continued confusion about the diagnosis of COPD and treatment choices”.[32]



88% of Healthcare professionals (HCP’s) felt COPD was self-inflicted

50% of HCPs admitted to being unaware of COPD guidelines

70% (7 out of 10) patients believe their COPD symptoms are mild to moderate

Source: COPD Resource Needs Assessment Survey (2004)

But educational initiatives, useful as they are, can only go so far. They have little effect if HCPs choose to remain prejudiced or if patients remain in denial about their condition. The 2014 GSK survey found patients significantly underestimate the severity of their symptoms. While more than half (54%) of US participants reported clinically significant dyspnoea, the majority (70%) classified their COPD as only mild or moderate in severity. The study authors report that this demonstrates “a disconnect between the level of symptoms and [patients’] own subjective assessment of the disease”.[33]

And, despite the efforts of the Global initiative for chronic Obstructive Lung Disease (GOLD) to provide clinicians with updated information on managing COPD, widespread confusion about the condition persists. Nurse educator Janet Delooze runs a self-referral clinic for breathing disorders in New Zealand and says she has come across significant numbers of people who are misdiagnosed as well as undiagnosed. “If they are not diagnosed with COPD, they are not treated appropriately,” she says. “Our job is to get people on the right track and that often means suggesting to the GP that COPD should be investigated.” Entrenched attitudes continue to challenge the experts. Not recognising, and therefore not acting on, symptoms can delay diagnosis, which is now recognised as a major opportunity for patients, pharma companies and healthcare systems by enabling clinical intervention before lung function is severely impaired. Post-hoc analyses of data from three major COPD studies – TORCH (Towards a Revolution in COPD Health), UPLIFT (Understanding Potential Long-term Impacts on Function with Tiotropium) and ECLIPSE (Evaluation of COPD Longitudinally to Identify Predictive Surrogate End-points) – found the decline in pulmonary function is faster in the earlier stages of disease.[34]

Patient attitudes about their condition in this and other ways are the major contributory factor to their health via increasing adherence to medication, taking more exercise and generally feeling they, together with their doctors, are in control of what is happening to them.[2]

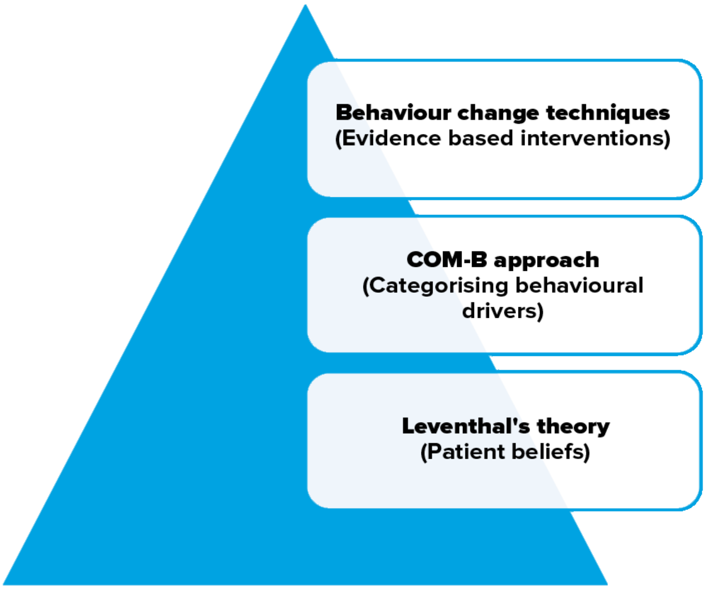
Key takeaways

- **Ignorance about COPD:** Educational programmes to raise awareness among the general population and specialised educational materials aimed at helping HCPs make the correct diagnosis and support, rather than blame, their patients.
- **Denial of COPD:** Personalised interventions aimed at helping people who are diagnosed accept their condition and appreciate that there are medicines and lifestyle choices that can improve their prognosis.

Changing behaviour

Changing behaviour is critical to changing outcomes in COPD. The most important thing in enabling people to change their behaviour is to understand how they make sense of their illness and what drives their behaviour. That enables personalised interventions to be created that address issues specific to individual patients, as illustrated in Figure 2.

Figure 2: Three steps to creating effective intervention programmes



Patient beliefs: Leventhal's common-sense model of illness

Evidence across multiple chronic conditions shows that, in order to cope with an illness, patients form their own beliefs about the nature of their condition in accord with Leventhal's common sense model of self-regulation of health and illness. This proposes that patients process what is happening to them around distinct components which, in turn, determine their coping behaviour. It maintains that each patient has their own ideas about the identity, cause, timeline, and consequences of their illness. Some patient models also incorporate beliefs about the cure and controllability of their condition.[35] Overviews of research in this area, based on differing methodologies across a range of different clinical conditions, confirm the consistency and validity of these five components of patients' illness representations.[36]

The model is dynamic. If people's perceptions of illness change so do their coping strategies. These assumptions were tested when 87 patients with COPD who were on a pulmonary rehabilitation programme were invited to complete the Illness Perception Questionnaire – Revised (IPQ-R) before and after treatment. The researchers rated the degree to which the rehabilitation had led to desired outcomes and found patients who were more convinced that their participation had contributed to this were also less concerned about the negative consequences of COPD, had stronger perceptions about the variability in symptoms and had stronger perceptions of personal control over their condition.[37] As a result, these patients were likely to be more actively engaged in managing their illness and treatment. The holding of more helpful and accurate perceptions, in turn, has been shown repeatedly to lead to more positive self-management behaviours and psychological outcomes.

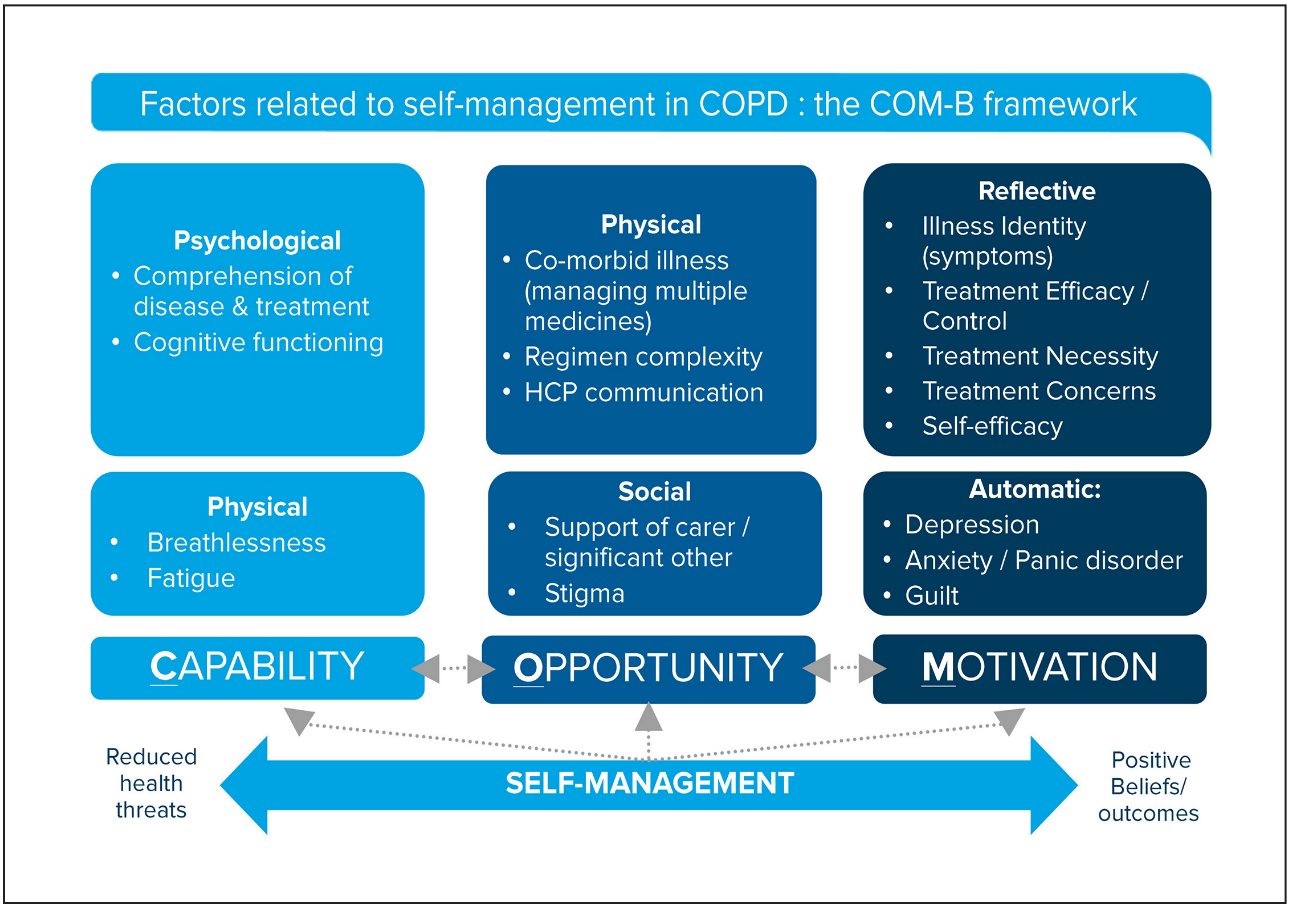
#rwCOPD (Weinman)
The key to understanding patient's 'coping' strategy is to look at thoughts, ideas and emotions; otherwise picture not complete.

Patient behaviour: COM-B approach

Leventhal's theory has been very useful for understanding why and how individuals respond to their illness in different ways. In terms of designing appropriate interventions, the COM-B model provides a more detailed framework of understanding by breaking down the many factors involved in self-management and in adopting a healthier lifestyle into three descriptive groups that all affect behaviour:

- CAPABILITY: Factors concerning a patient's physical and psychological ability to adhere to medication regimens and lifestyle changes, including, for example, whether they can use their inhaler properly and if they can understand the dosage instructions.
- OPPORTUNITY: Factors external to the patient that might include the quality of social support, access to healthcare and pulmonary rehabilitation or whether they can afford medication.
- MOTIVATION: Factors related to the patient's beliefs about how their condition developed and the effectiveness of treatment. This also includes their confidence to manage their condition and their levels of depression or anxiety.

Figure 3: Factors related to self-management in COPD; the COM-B framework



#rwCOPD (Weinman) opportunities for true support include changing mindsets challenging negative beliefs, reducing anxiety...

The benefit of this model is that it allows for interaction between factors. Capability, opportunity and motivation all have a direct effect on adherence or self-management. Equally, capability and opportunity can affect someone's motivation, which impacts their adherence. For example, if someone has a limited understanding of their disease and treatment then this could have a negative effect on their perceptions of their need for treatment.

This model is a good starting point when thinking about a patient support programme to identify which psycho-social factors to address in order to give patients the best chance of success.

Personalised interventions

One of the challenges of modern healthcare is to translate understanding of human behaviour into large-scale but customised interventions that can deliver demonstrable benefits for patients, healthcare systems and programme sponsors, usually the manufacturers of COPD medication.

Evidence from a large number of research studies has shown us that there are many different psychosocial factors that can cause non-adherence. These factors will vary from patient to patient over time, as their experience of the illness and treatment or their social circumstances change.

This is why we need to *'get personal'* in our understanding and management of non-adherence and to ensure that patients receive support strategies and interventions that are personalised based on their own individual adherence barriers. At the very beginning of any patient support programme, we need to screen each patient carefully to uncover the specific reasons for their non-adherence in order to know what underlying factors or beliefs need to be addressed.

Atlantis Healthcare works with a multifaceted approach where messages are conveyed via various channels such as a website, email, short messages (SMS), magazines and personal calls from a health coach. It takes what is known about the patient population, stratifies it via the COM-B approach, and then creates content and delivery methods that have been shown to work in those groups.

Key takeaways

- Understanding why a person is not adherent to medication or lifestyle change is a necessary first step to improving adherence and therefore outcomes.
- Patients must be individually screened regarding their attitudes to disease and treatment to enable interventions to be personalised and increase their chance of success.

Particular challenges in COPD

The management of COPD presents particular problems. Adherence to medication, for example, is challenged by the chronic nature of the disease; the use of multiple medications; periods of symptom remission; depression and anxiety, which are significant co-morbidities; and individual patient beliefs. In addition, there are various distinguishing features of the disease that must be addressed to improve outcomes.

Nature of COPD symptoms

- Challenge: Getting people to understand the nature of their symptoms and the importance of medication. Most people are on two treatments: one which gives immediate relief by opening up the airways and another daily inhaler, which helps prevent deterioration by reducing inflammation in the airways.
- Implications for self-management behaviours: Education regarding the importance of medication to prevent disease progression and the roles of the different treatment.
- Opportunities for intervention: Designing personalised programmes to improve adherence to the daily treatment where the effects are not immediately obvious, including challenging perceptions about the controllability of the condition and building self-efficacy to manage.

#rwCOPD only with ‘good self-management’ can a patient really be in charge of his/her condition!

#rwCOPD Totally agree. Question is how to enable this level of self-management

Vicious circle of inactivity

- Challenge: To break a vicious circle of inactivity whereby patients are reluctant to take exercise because it makes them breathless, which causes anxiety, leading to patients becoming more breathless and causing greater resistance to physical exercise.
- Implications for self-management behaviours: Education and community support to understand the importance of exercise, not necessarily in terms of going to the gym, but in everyday activities such as walking to the local shops or taking the stairs rather than a lift. Specifically, patients must be able to appreciate the difference between a COPD symptom and the natural outcome of an elevated heart rate from exertion.
- Opportunities for intervention: Designing personalised interventions to help people think about what is happening when they take exercise and to help them manage their anxiety, via techniques such as mindfulness or slow breathing, to break this cycle of inactivity. Pacing techniques, derived from cognitive behavioural therapy, can also help people meet this challenge, by getting them to set daily activity timeframes, encouraging them to be active each day without overdoing it on ‘good’ days and thereby tiring themselves out.

Inhaler technique

- Challenge: Significant numbers of patients have not been taught to use their inhalers correctly. An evaluation of inhaler use, in 316 patients suffering from asthma or COPD, found 89% made at least one mistake in the inhalation technique.[38] The most common skill error, shown by 69.6% of patients, was not continuing to inhale slowly after actuation of the inhaler. The non-skill item that 65.8% patients had difficulties with was exhaling before the inhalation. Patients may also struggle with dexterity if they have arthritis, for example.
- Implications for self-management behaviours: HCP training and educational support to overcome the many misconceptions patients have about using their inhalers. “Some expect to feel an effect when they shouldn’t with the right technique,” says Dr Kevin Gruffydd-Jones, Royal College of General Practitioners (RCGP) respiratory clinical lead and a GP in Wiltshire, England. “With a metered-dose inhaler, if you inhale too quickly, it hits the back of the throat, you feel it and think the treatment is working. But actually, with the proper method, taking a slow breath inwards over five to 10 seconds, users may not feel it reaching the lungs and think it hasn’t worked.”[39]
- Opportunities for intervention: Personalised training programmes for patients, as well as educational materials and applications for HCPs to help them better educate their patients.

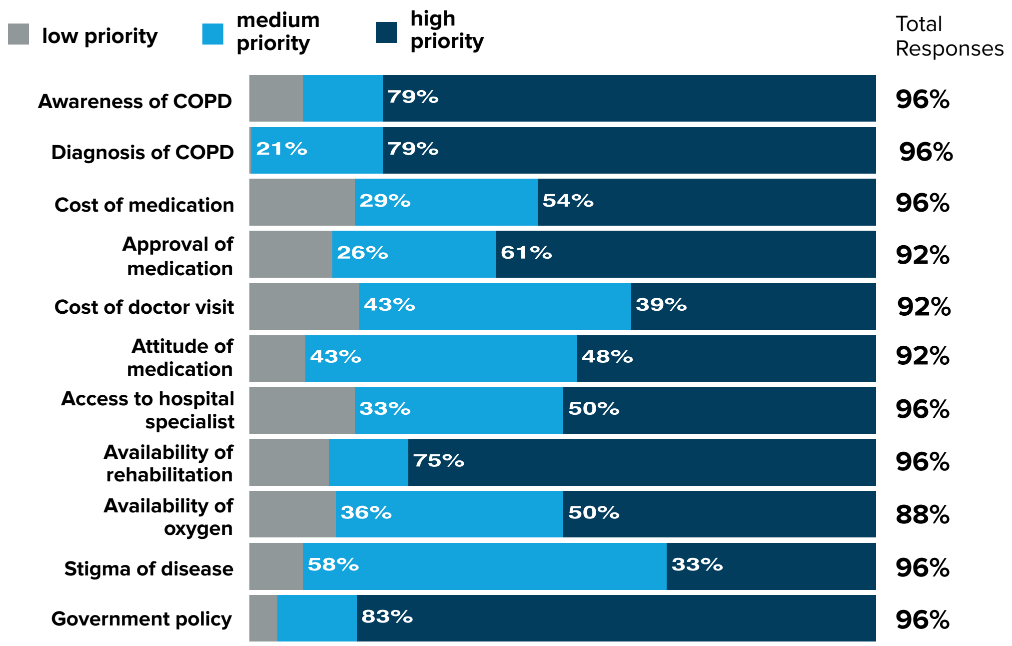
Overcoming stigma

- Challenge: Patients, particularly if they have been smokers, can feel a sense of guilt about their condition. This can be compounded by HCPs who take the view that people with COPD have not helped themselves in the past so why should they start now?
- Implications for self-management behaviours: Stigma creates a barrier to coming forward, getting diagnosed and starting to take steps towards better self-management. It also reduces the likelihood of patients approaching their HCPs to ask for help.
- Opportunities for intervention: HCPs must be encouraged to work towards boosting the confidence of patients by making sure patients/carers understand there are things they can do to help their condition. Patient attitudes about their condition are the major contributory factor to their health outcomes via increasing adherence to medication, taking more exercise and generally feeling they, together with their doctors, are in control of what is happening to them.

Patient insights

Patient insights are central to creating effective interventions in any condition. These come from academic research and, increasingly, from patient organisations. The COPD Foundation, for example, conducted a survey during an initiative to establish a global community of patient leaders at the first Global COPD Patient Leaders' Summit in Madrid, Spain, in November 2014.[40] Although attendee numbers were small, they represented 23 countries, five COPD patient organisations and eight physicians who collaborate with the patient community. Their views on the perceived importance of the main issues affecting COPD patients and their caregivers are revealed in Figure 4. The top priorities are awareness and diagnosis of the condition, the availability of pulmonary rehabilitation programmes and government policy.

Figure 4: Importance of issues affecting COPD patients and caregivers



Source: COPD Foundation survey, November 2014.

John Walsh, president of the COPD Foundation, states that the biggest challenge within the COPD community is a lack of awareness about the condition. Many survey respondents stated, for example, that they wished they had known smoking does not just cause cancer, the risk of which they perceived as relatively small. Respondents also expressed frustration at a general lack of pulmonary rehabilitation services, creating opportunities for greater collaboration between healthcare providers, healthcare systems and pharma companies to not only provide more rehabilitation but also personalised interventions targeting the hardest to reach patients or those who would benefit the most.

#rwCOPD for the ultimate patient support programme all stakeholders in the patient journey need to be involved; a committed community.

#rwCOPD absolutely although is it clear to each stakeholder what their responsibility is?

When asked about the worst aspects of having COPD, a low quality of life was the most frequently mentioned response, along with references to symptoms, exacerbations, limited activity and the incurable nature of the disease. Patients held themselves and cigarette manufacturers equally responsible for their COPD, with about a quarter referencing genetics.[3]

These results are echoed in the work of local patient organisations. Dr Penny Woods, chief executive of the British Lung Foundation, for example, mentions various initiatives to improve awareness. These include Breathe Easy support groups across the UK, lung-testing events and an assortment of educational resources to support better self-management techniques. But for all this work and the volume of educational materials being produced, there is a persistent block about seeking help at early stages of the disease and believing that something can be done.

#rwCOPD Too many words are out there that patients don't understand.

These are obstacles that can easily be overcome via programmes, sponsored by either pharma companies or local healthcare organisations, offering free health checks. "People often think they can ignore having a cough or feeling breathless," says Dr Woods. "However, these aren't just signs of being unfit, getting old or a smoker's cough. They can be symptoms of lung disease. It is vital that anyone who has had a cough for longer than three weeks or who feels breathless through non-strenuous exercise visits their doctor."[41]

Linda Thompson, executive director of Asthma New Zealand, agrees the most important thing is for patients to seek help early. "There is significant misdiagnosis of COPD as well as under-diagnosis," she says. "People tend to just soldier on. One of our volunteers with COPD got an infection recently and thought she could deal with it herself. If she had sought help she wouldn't have ended up in hospital with oxygen levels that were off the scale."

Living with COPD

Nurse educator Janet Delooze runs a clinic for breathing disorders for Asthma New Zealand and describes what life is like with severe COPD. "A person with severe COPD experiences constant breathlessness," she says. "They can't do things like take a shower without becoming absolutely exhausted. Their whole life has to adapt to their mobility deteriorating to such a degree that they lose independence. They have to ask for help and accept that this is their life now, that there are things they will never be able to do again. Their whole identity changes and there is a lot of anxiety and depression around this. It is like any long-term condition. People know they have this constant problem that is deteriorating and interspersed with acute exacerbations where they recover but don't get back to where they were. It is a vicious circle. Once you are down and depressed you don't go out, you don't exercise, you don't socialise and the situation gets worse."

> **It is a vicious circle. Once you are down and depressed you don't go out, you don't exercise, you don't socialise and the situation gets worse.**

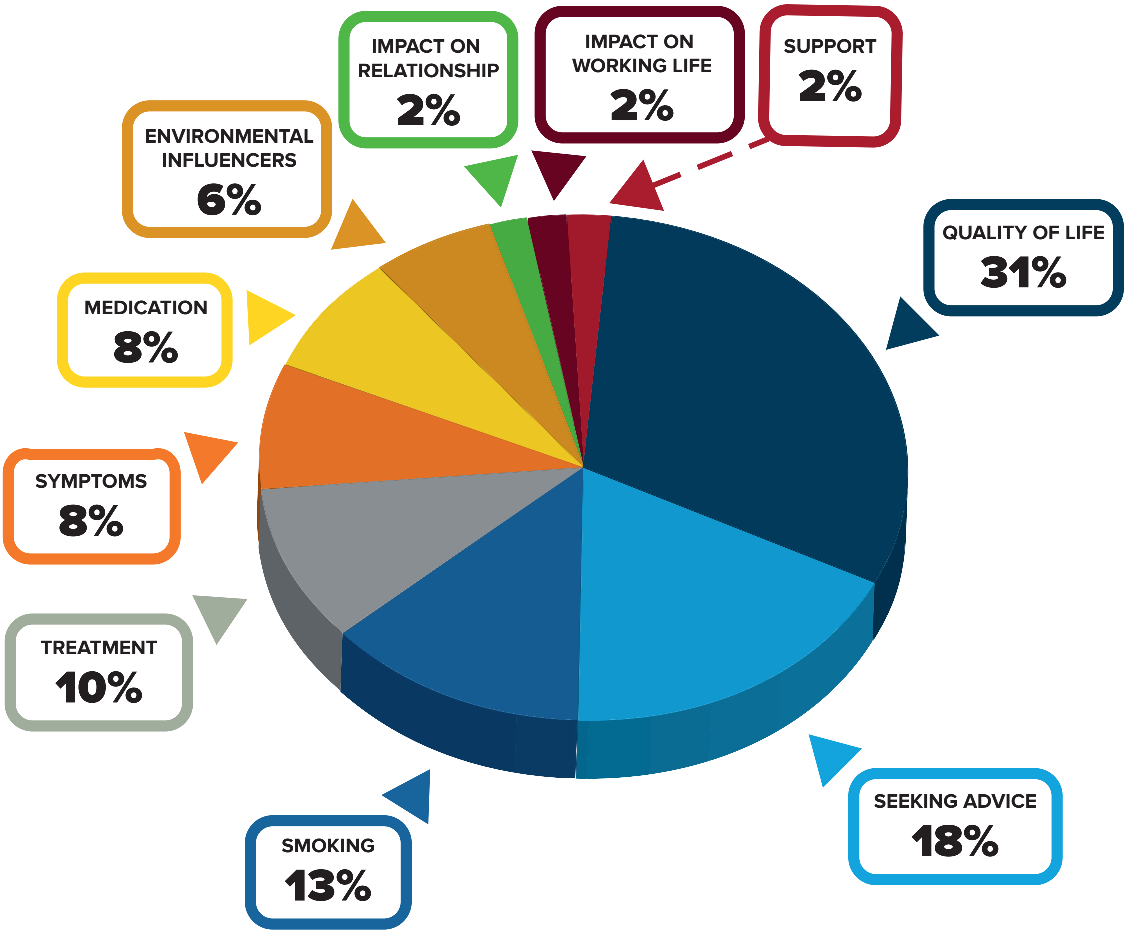
Qualitative research conducted by Atlantis Healthcare asked patients and carers in Germany and Spain what it is like to live with COPD, why treatment is not always taken, and how they make sense of their condition. The responses were similar across both countries and comprised the following themes:

- Low levels of understanding about the condition. Patients often try to play down its impact, ignoring its progressive nature.
- A sense of guilt and anger at themselves at having brought the condition on themselves by smoking.
- Lack of control in being unable to predict symptoms and feeling on a steady decline for which there is nothing they can do.
- Impact on quality of life, including poor sleep, restricted activities, fatigue, low mood, and a vicious cycle of breathlessness and anxiety.
- Maladaptive coping by avoiding activity and not taking maintenance treatment.
- A sense of loss both in terms of what they cannot do any more and plans for the future that they no longer see happening. These limitations were also perceived as losses by the caregivers, who felt equally restricted.
- Low regard for COPD patients from some HCPs who feel they do not help themselves.

Social media: what COPD patients are talking about

Patient conversations in social media represent another perspective on the effects of COPD. Janet Gunner, managing director of Digital Media Intelligence (DMI), a UK-based company that analyses social conversations, explains that data from online sources pertaining to COPD was collected from four countries (the UK, the USA, Australia and New Zealand) during the month of November 2014. Although the same search terms were used, they led to vastly different volumes of data. In the USA, for example, 156,921 posts were identified; in the UK, there were 35,351; in Australia, 4,271 and in New Zealand just 1,712. These posts were filtered down further for relevance, which meant they must have a reference to COPD and be posted by a patient. A maximum of 250 per country were then subject to human interpretation and analysis to group them into the ten most common types of conversation, as shown in Figure 5.

Figure 5: Key topics in COPD conversations in four countries, November 2014



Source: Digital Media Intelligence

#rwCOPD COPD Foundation has helpline with COPD patients supporting and helping COPD patients 10,000s of calls and real successes

#rwCOPD challenge is how to scale as platform is great taking beyond, through social media, patient to patient communities...

The largest topic patients chose to talk about was the impact of COPD on their quality of life, scoring 31% of conversations. If the impact on relationships and on working life is included, this rises to 35%. Efforts to seek advice created 18% of conversations, smoking 13% and treatments 10%.

A closer look at individual conversations suggests considerable confusion, confirming the need for greater awareness of COPD and its treatment. In particular, people report their shock at being diagnosed after routine employment medicals, about how the medications work, about conflicting advice as to whether they have chronic bronchitis or emphysema and about the considerable effect the condition has on all aspects of their lives.

Key takeaways

- **Low levels of understanding about COPD coupled with high levels of denial and prejudice combine to create fertile grounds for personalised intervention programmes.**
- **Despite the progressive effect of COPD on a person's quality of life, many patients feel there is nothing that can be done.**

The rise and rise of health psychology

Patient organisations have a role to play in raising awareness of COPD. Howver, a more significant contribution in terms of helping people change unhealthy behaviours comes from health psychology. Professor John Weinman, Professor of Psychology as applied to Medicine at the Institute of Psychiatry, King's College, London, says recognition of the psychological factors involved in health has risen sharply over the past 30 years. "Increasingly, people realise not just how dependent health is on behaviour but also that, once the factors driving unhealthy actions are understood, specific interventions, and there are many, can be deployed to help people change their behaviour either by stopping smoking, exercising more or taking their medication appropriately."

Leventhal's work is important, Weinman continues, because he explained what has been verified again and again, which is that people go through similar responses when they experience a threat to their health. "First, people ask what the threat is. Leventhal describes this as perceived identity, the diagnostic label, which is the COPD or breathlessness if that is how people choose to describe it," says Weinman. "Second, they try to answer why they got this threat. Third, they try to answer how long it will last. The fourth thing they question is the effect it will have on them in the short and long term. The last set of questions people try to answer are around what can be done, what can I do to improve or diminish the impact of this condition on my life? What can other people do, what can treatment do? Leventhal refers to that as the cure-control type belief. Essentially there are these interconnected beliefs that form a person's idea about what's happening in their body. Those beliefs, in a very direct way, drive and determine what they do."

A different way of thinking

> 20% of patients remained persistent with maintenance therapy at one year

People are constantly appraising what they are doing. A recently published study conducted by researchers at the Strathclyde Institute of Pharmacy and Biomedical Sciences, UK, looked at the adherence rates of 13,322 patients, 10,521 of whom had asthma and 2,801 had COPD.[42] The study, using prescription redemption rates rather than patient reporting as a measure of adherence, found less than 20% of patients remained persistent with maintenance therapy at one year.

"It may be they didn't see an immediate benefit," says Weinman. "Their thinking is they have a condition, are committed to trying a treatment and believe there is something doctors can do. They start taking the treatment but if they do not see any benefit their evaluation process leads them to think the treatment is no good and maybe their condition isn't controllable, at least not by this treatment, and they give up. Partly because of that feedback, they start to develop a different way of thinking about their condition."

There is also a parallel emotional response. "Not only do patients have to cope with how they think about the disease, but there will be coping behaviours to deal with any emotions the condition activates," he continues. "People with COPD, for example, have relatively high rates of depression, partly because the condition can be so debilitating, physically and mentally. These two things run in parallel and are part of the whole pattern of ways that people adapt to, and try to deal with, illness. It is a moving picture of a dynamic set of factors that provide a good description of how individuals react. It's a really fundamental way of looking or understanding how individuals are coping with their condition that holds true for any disease."

Key takeaways

- **Recognition of the contribution of health psychology to improving patient outcomes has risen sharply over the past 30 years.**
- **Understanding how individual people respond to illness is critical in helping them change their behaviour towards medication and exercise, thus leading to improved outcomes.**

Barriers and facilitators of adherence

The Leventhal model is used to tackle the challenges to improve adherence, defined here as 'the extent to which a person's behaviour in terms of taking medications, following diets, or executing lifestyle changes coincides with medical or health advice'. Adherence to medications generally is affected by how complicated the regimen is, the frequency of dosage, route of administration and perceived symptom relief. All of these are important factors in COPD.

According to an overview presentation on adherence in COPD, Professor Ruben Restrepo of the University of Texas Health Science Center, USA, reports that, on average, 40%–60% of patients fail to take their medicines appropriately. Moreover, only one in ten is able to use their metered dose inhaler correctly.[4]

The main types of non-adherence to therapy, which can be intentional or non-intentional, are: underuse, the most common type of non-adherence in COPD patients; overuse, particularly in reliever medications; and improper use, usually in the operation of inhalers.

All are affected by the underlying beliefs patients hold about their condition.

> **Only one in ten [patients] are able to use their metered dose inhaler correctly.**[19]

Barriers to adherence

Restrepo confirms the strong psychological component in COPD patients that can act as a barrier to adherence. "Significant differences in health beliefs, experiences, and behaviours are observed between COPD patients with different levels of adherence," he says. "While education plays an important role in modifying beliefs, patients are likely to modify the recommended therapy based on how they feel or their level of dyspnoea (breathlessness)."[4]

He goes on to report that COPD patients with suboptimal adherence have insufficient understanding about their illness and the options for managing it, show a low level of satisfaction with, and faith in, their physician, and rely more on natural remedies.[43] They also perceive the management of COPD as a mystery and show low confidence in drug therapy. [43, 44, 45]

The role of beliefs, experiences and health behaviours as predictors of low adherence to treatment was confirmed in a 2005 study of 276 patients with COPD.[43] This found such factors, listed in Figure 6 in order of statistical significance compared with subjects with high adherence, were more powerful predictors of adherence to medication than either socio-demographic or clinical factors. The italicised factors were found to explain almost 20% of the variance in this study.

Figure 6: Beliefs, experiences and behaviours affecting adherence in COPD

BELIEFS

- I do not have sufficient understanding about my illness
- My doctors are not very knowledgeable
- Natural remedies are safer than medicines
- My doctors have limited management options to offer me
- I do not have sufficient understanding about the options for managing my illness
- The management of my illness is a mystery for me

EXPERIENCES

- It is unpleasant to use some of my medications
- It is physically difficult to handle some of my medications
- I am not satisfied with the information my doctors share with me
- My doctors are not compassionate
- *My doctors don't spend adequate time with me*

BEHAVIOURS

- I get confused about my medications
- *I vary my recommended management based on how I am feeling*
- I put up with my medical problems before taking any action
- I make changes in the recommended management to suit my lifestyle

Facilitators of adherence

Reminder systems and computer-tailored feedback have been shown to be helpful in improving adherence. This was the conclusion of a meta-analysis looking at 11 randomised controlled trials of reminder interventions (phone calls, text messages and interactive voice response systems).[46] The authors went on to suggest that reminder interventions can also help reduce intentional non-adherence if the messaging is appropriate to the patient's own perceptions. They suggested, and this is highlighted in other research, that reminder devices may be more effective when combined with additional strategies such as social support, providing feedback to patients and tailoring treatment plans to patients' needs.

A meta-analysis of 88 studies investigating the effectiveness of computer-based feedback, including computer, print or phone-based communication, found tailored interventions seem to be effective and, importantly, that they remain effective in the long term.[47] In particular, they found dynamic feedback (to assess intervention variables before each feedback session) is more effective than static feedback (feedback based on only one assessment).

Interactive voice response interventions (IVR), meanwhile, have proven particularly effective with two studies reporting a significant increase in adherence in patients taking inhaler medication who had received IVR compared with controls.[48,49] Regarding the nature, tone and frequency of reminder messages, research is relatively scarce. However, one study highlighted the importance of the voice being clearly distinguishable from automated telemarketing calls and marked as part of their care plan.[50]

Research has also shown cognitive-behavioural interventions to be effective in changing negative perceptions of COPD and resulted in improved coping, physical functioning and quality of life.[51] And home telehealth has been found to reduce rates of hospitalisation and emergency care, and to result in better quality of life and patient satisfaction.[52]

Predictors of adherence to COPD treatment

The following predictors are not present in every COPD patient. However, where these predictors are present they can, and are likely to, influence adherence to treatment.

- Individual patient beliefs about COPD
- Patient beliefs that they do not need to take medications when feeling well (perhaps because they are encouraged to increase dose when symptoms are severe)
- Perception of necessity for the treatment (greater for corticosteroids, which are used in exacerbations and for shorter periods of time)
- Complexity of dosing schedules for COPD and common co-morbid conditions such as asthma, hypertension, osteoporosis and cardiovascular diseases
- Poor instructions for, and performance of, inhaler technique
- Disease severity (adherence is higher in more advanced stages of the disease as a result of more severe symptoms and more frequent contact with clinicians)
- Concerns about side effects (up to 90% of patients report side-effects of COPD medication)
- Beliefs of partners and carers about COPD and medication (likely to have an impact, but have not yet been investigated in COPD)
- Patients who experience clinical depression (prevalent in 19% – 37% of COPD patients) are more likely to present an adherence risk
- Patients who experience anxiety (prevalent in 35% of COPD patients) are more likely to present an adherence risk
- Decline in memory (such as increased forgetting) and problems understanding instructions for use of medical devices.

#rwCOPD Existing solutions to support COPD patients are patient centric to a degree but need to improve

Intervention programmes in COPD

According to Professor Weinman, who helps design interventions for Atlantis Healthcare, the key aspect is to personalise the programmes. “At the beginning of any programme patients are asked to fill out a screener in which they answer questions about their beliefs, their medicines and their skill in organising their day-to-day activities so they are able to take their medicines on a regular basis,” he says. “This is to find out what the issues are for them. Then, we put together a combination of interventions which address those issues. They don’t have to be expensive. We developed a programme a couple of years ago for young patients with asthma who were non-adherent, providing focused text messaging. These were not reminders but messages designed to change the way they thought about their asthma and their treatment, and it was very successful in doing that. Some interventions do use multiple media and for patients who are at high risk of non-adherence, adding in things like nurse phone calls is great if that’s needed, but that isn’t necessary for all patients.”

Framing messages for maximum value

Solutions are constantly being tested. Original research by Atlantis Healthcare presented at the 2014 British Psychological Society Division of Health Psychology conference explored the key principles around framing short messages to COPD patients to maximise their ability to drive better adherence. Cognitive interviewing techniques were used on 12 UK adults with COPD to evaluate the relevance and understanding of various messages. Given the personal nature of some of the messages, the participants were also asked how the questions made them feel to ascertain any psychological impact from the messages.

The idea was to discern the most important factors to consider in creating messages, which are used as reinforcements within a wider behavioural-change programme, to optimise their acceptability and subsequent effectiveness. The research explored how well people understood the messages, what the messages made them think about, the relevance of the language used and how the messages made them feel.

The results led to the following key messaging recommendations:

- Messages should be accurate, concise and specific to the medication the participant is taking. Potential issues of confusion should be identified and either rephrased or removed (e.g. take once a day because it works for 12 hours may be confusing as people consider a day to be 24 hours).
- Where possible, statements should be kept general enough so as to not exclude some recipients, but also balanced with being informative (eg, talking about potential seasonal changes as opposed to being specific about winter/summer).
- Messages should be framed in a positive way – focussing on the benefits of doing something as opposed to the ‘consequences’ of not.
- A greater understanding of the person with COPD in relation to disease stage, experiences and current behaviours may help to reduce the likelihood of them receiving messages that are not relevant.
- Even brief messages have the potential to elicit an emotional or psychological response so it is important that this is considered when creating messages and appropriate signposting to support is made available.

What does a good support programme look like?

More and more healthcare systems are looking to implement behavioural-change programmes. The first critical factor for success is to base everything on as deep an understanding as possible of an individual’s needs and their individual risk factors. It also needs to do something other than giving people information. If information alone led to change no-one would smoke, drink to excess or overeat.

It’s about motivating people, upskilling them and imparting confidence so they are able and motivated to carry out helpful behaviours and maintain these behaviours over time. A good patient support programme doesn’t just understand the individual. It gives them the tools, the encouragement and the evidence-based support so they can realise better outcomes. It’s not telling people what to do, but supporting them so they recognise what needs to be done and are skilled and confident enough to make those changes.

To create a good patient support programme it’s necessary to understand the patient journey and the key moments and stakeholders involved to reach the entire circle of care. The ideal programme considers more than just the patient and has different objectives and communication strategies with HCPs, carers, pharmacists and patient associations, recognising the impact of all these stakeholders on the motivation and wellbeing of the individual with COPD. Additionally, the different level of involvement of the actors will make a noticeable difference in the enrolment of patients and scaling of the programme.

Choosing the right channels to deliver the programme is also key to achieving the desired outcome. Understanding the target patient group and their interests within a particular region is a key starting point to select the media that will support the delivery of the programme. Local culture might request the use of printed material instead of digital, and legislation defines content and process. In a COPD patient support programme delivered in Spain, for example, patients noted the telephone support given by nurses as their preferred communication channel, followed by the magazines written by the health psychologists to address their unhelpful beliefs and the workbooks to complete the interventions. A good support programme also delivers tangible results. For payers interested in a reduction in the associated costs of a chronic disease, behavioural-change programmes in COPD are relatively common because the potential gains to healthcare systems and patients are significant. Il Economista reports that the average cost in Spain from diagnosis to death of a COPD patient is €9,730 if they are started on treatment early. This rises to €43,700 if treatment starts after the disease has progressed. Such figures have prompted recognition at the highest levels that a partnership approach between industry and healthcare systems is the way forward in respiratory disease.

The NHS England Outcomes Strategy for COPD and Asthma, published in May 2013, for example, includes a Foreword from Professor Sue Hill and Dr Robert Winter, Joint National Clinical Directors for Respiratory Disease, in which they say, “We have made it clear that in order to deliver improved outcomes for people with these and other respiratory diseases, it requires a true partnership approach.”[54]

The pharma industry usually measures the return on investment by combining objectives in adherence and persistence with the rise in brand perception and value given to the molecule from providing an extended service to the patient and HCP.

Partnership approach in New Zealand

COPD is estimated to affect 15% of New Zealanders over the age of 45 and is the fourth leading cause of death after cancer, heart disease and stroke.[21] It also represents one of the most significant healthcare disparities in the country, with Māori people being more than five times more likely to die from COPD-related causes than non- Māori, as well as being affected by COPD up to 20 years earlier. [22]

Jared Poppelbaum, Director of Population Health at Atlantis Healthcare, explains how steps are being taken at a national level to smooth the way for effective intervention programmes to improve these statistics for COPD and other long-term conditions. The National Health IT Board, he says, is integrating the administration systems across all providers, including primary and secondary care, so that electronic healthcare records and care plans can be shared. These advances will improve patient-centred care that will ultimately deliver better patient outcomes and enhance the ability of health systems to measure the effectiveness of support interventions. More importantly the linking of records will allow for earlier identification of patients in need and the deployment of targeted, cost- effective interventions to support self-management.

“An electronic link between GPs who write the scripts and pharmacists who dispense them creates an opportunity to identify patients who are struggling with adherence without having to rely on a healthcare professional to make patients aware of support programmes,” he says. “This is important because, traditionally, participation rates in initiatives run by the District Health Boards in, for example, pulmonary rehabilitation, reach less than 1% of patients [55] despite compelling evidence to show they really do improve outcomes. By utilising these integrated national health systems we can ensure all eligible patients are offered support and we can start reducing some of the significant health inequalities that exist in New Zealand.”

Atlantis Healthcare is currently delivering a programme designed to support individuals with diabetes improve adherence to their oral medications. While the programme is funded and supported by the New Zealand health system, Atlantis found that patient enrolment was suboptimal through traditional channels. “We needed to be innovative to solve the enrolment challenge,” Poppelbaum says. “We are working with Health IT vendors to create a national platform that will enable Atlantis Healthcare and other programme providers to reach the right patients at the right time. During the development of the platform, the patient will be paramount to the process and issues such as acceptability and privacy will be extensively tested. Rather than automatically enrol patients from electronic records, we will extract the minimum amount of information that allows us to contact an eligible patient, make them aware a funded support programme is available for them and invite them to participate.”

Medicines adherence is just one part of the much broader patient self-management need. While the development of electronic shared-care planning tools is helping to co-ordinate HCP-directed care, there is a need to integrate innovative, cost-effective mobile health and telehealth solutions alongside standard care pathways. This will extend self-management support beyond the clinic and into the day-to-day lives of patients.

#rwCOPD we can learn from patient communities. There is opportunity to collaborate on solution design & personal interventions

Pharma perspectives

Pharma companies compete in a global COPD market that was worth nearly US$12 billion in 2013. Their research has prompted a number of new and more efficient and/or convenient drugs, mainly the long-acting beta-agonist (LABA)/long-acting muscarinic antagonist (LAMA) combos. These are expected to accelerate market growth at a compound annual growth rate of 8% to reach close to US$17.5 billion by 2018.[56] A report from Decision Resources suggests the once daily LABA/LAMA fixed-dose combinations will capture more than a third of the COPD market by 2021.[57]

In today's patient-centric and outcomes-led world, pharma companies are highly incentivised to invest in how their patients use their products and indeed, value-added services have become a significant new avenue of business. A US study conducted by management consultants Accenture in 2014 found 76% of patients now expect such patient services. Shawn Roman, managing director in Accenture's life sciences group said this was a "tremendous opportunity for pharmaceutical companies to become more engaged with the patients they treat and truly understand how to help deliver a better patient outcome."[58] That opportunity is as much in medicine optimisation and securing a better reputation among HCPs as it is in increased sales, which happens as a result of people being diagnosed earlier and improved adherence rates.

Non-drug competition

As in other areas of medicine, new sources of competition from technology companies are emerging to help patients better manage their condition by increasing their self-knowledge of how behaviour affects their performance. UK-based Aseptika, for example, is working on a smart watch, known as BuddyWOTCH, which, among other things, monitors blood oxygenation levels in COPD patients on a continuous basis.[59] The WOTCH component incorporates medical sensors for capturing data on: Walking, Oxygenation, Temperature, Chronicle (image capture of medication, food and liquids) and Heart rate. Data on these parameters are automatically transmitted, i.e. without user operation, to simplify self-monitoring. By combining this data with a sputum test, which can predict the onset of lung infections, or exacerbations, it is being marketed as an integrated monitoring and alert system that is scheduled for beta testing by the end of 2015.

Conclusions

Everyone within healthcare is motivated to help patients better adhere to their COPD medications because the results consistently translate to better outcomes and lower healthcare costs. But to develop programmes that actually change behaviour requires a profound understanding of why people behave as they do and a dedicated focus on supporting patients to become active agents in their wellbeing. In an ideal world, this would be the remit of healthcare systems or the HCPs who treat COPD patients. In reality it falls to teams of committed individuals who, by their efforts, are helping to change how healthcare is perceived and delivered by demonstrating what a patient-centric approach really means in chronic conditions such as COPD.

From this report we have learned there is continued confusion from patients and HCPs about the diagnosis of COPD and guidance on treatment choices. Clearly more needs to be done in terms of facilitating HCP/patient education about the disease and utilising new technology to encourage and support two-way dialogue as information sharing can help to improve outcomes.

Pharmaceutical companies

- A disconnect between the level of symptoms and patients' subjective assessment of the disease highlights the opportunity to provide personalised patient support programmes that offer not only valuable information but also much-needed emotional and psychological support to help overcome personal beliefs and adherence barriers.
- Personalised interventions should be aimed at helping people who are diagnosed to accept their condition and appreciate that there are medicines and lifestyle choices that can improve their prognosis.
- Working in collaboration with patient organisations to develop and deliver educational programmes that raise awareness among the general population to help detect early signs of COPD could also help enable people with COPD to seek an earlier diagnosis.

Non-pharma and HCPs

- The biggest challenge within the COPD community is a lack of awareness about the condition.
- Public awareness campaigns can help combat ignorance that the condition exists. Development of educational campaigns on COPD signs, symptoms and causes, and clearly explaining that breathlessness is not simply a by-product of ageing and/or factors such as smoking, but a sign of a progressive disease that can be significantly helped with medication and lifestyle change, can help to reduce the stigma associated with COPD.
- Improving patient access to healthcare and pulmonary rehabilitation programmes is a necessary first step. In addition, provision of specialist training/workshops to the healthcare community to ensure first-hand carers have the adequate skills to offer psychological support to people with COPD. It is also necessary to train community carers to spot the signs of COPD earlier to ensure quick referral to HCP for diagnosis and treatment, all of which can help improve patient health outcomes.
- Not recognising, and therefore not acting on, symptoms can delay diagnosis, which is now recognised as a major opportunity for patients, pharma companies and healthcare systems by enabling clinical intervention before lung function is severely impaired.

Patients

- Patient attitudes about their condition are the major contributory factor to their health outcomes via increasing adherence to medication, taking more exercise and generally feeling they, together with their doctors, are in control of what is happening to them.
- Patients must be individually screened regarding their attitudes to disease and treatment to enable interventions to be personalised. Increased access to lifestyle/disease information and educational materials can be enormously helpful.
- Increased online connectivity with HCPs via telehealth and sharing experiences via patient forums and social networks allows patients to feel more empowered and in control of their condition. Patient access to connected solutions and two-way sharing of personal data with the wider healthcare community, which acts as a COPD family, could also encourage positive beliefs to treatment, reducing anxiety and isolation experienced by those patients with limited mobility.
- COPD patients expressed frustration at a general lack of pulmonary rehabilitation services, creating opportunities for greater collaboration between HCPs, healthcare systems and pharma companies to not only provide more rehabilitation but also personalised interventions targeting the hardest-to-reach patients or those who will benefit the most.
- Top priorities for COPD patients are awareness and diagnosis of the condition, along with the availability of pulmonary rehabilitation programmes, which need to be supported by pro-active government policy.

Atlantis Healthcare your global behaviour change experts.

For more information on Atlantis Healthcare contact Louise Hart - Global Marketing Manager.
Email: Louise.hart@atlantishealthcare.com

Or go to:
www.atlantishealthcare.com/contact-us

in www.linkedin.com/company/atlantis-healthcare

Follow us @AtlantisHtweets

Watch our recent COPD webcast sponsored by Atlantis Healthcare:
Empowering COPD patients – creating patient-centric solutions to drive positive behaviour change.
View: http://bit.ly/rwCOPDwebinar

REFERENCES

1 **Rand, CS.** Patient adherence with COPD therapy. European Respiratory Review, December 1, 2005 vol. 14 no. 96 97-101.

2 **Vestbo, J et al.** Adherence to inhaled therapy, mortality and hospital admission in COPD. Thorax, 2009; 64:939–943.

3 **COPD Foundation – Global Advocacy Initiative**. Partners Report, December 2014.

4 **Restrepo R et al.** Medication adherence issues in patients treated for COPD.

5 **Landis S H et al.** Continuing to Confront COPD international patient survey: Methods, COPD prevalence and disease burden in 2012-2013. International Journal of COPD. 2014; 9: 597-611.

6 http://www.copdx.org.au/foreword (Accessed February 2015)

7 **Levack W, Weatherall M, Reeve J et al.** Uptake of pulmonary rehabilitation in New Zealand by people with chronic obstructive pulmonary disease in 2009. NZMJ 2012;125:23-33

8 **Barbára, C et al.** Chronic obstructive pulmonary disease prevalence in Lisbon, Portugal: The burden of obstructive lung disease study. 2013;19:96-105 http://www.elsevier.pt/en/revistas/revista-portuguesa-pneumologia-320/artigo/chronic-obstructive-pulmonary-disease-prevalence-in-lisbon-portugal-90205527#bib20

9 **Soriano, J et al.** Geographical Variations in the Prevalence of COPD in Spain: Relationship to Smoking, Death Rates and other Determining Factors. Arch Bronconeumol. 2010;46:522-30 - Vol. 46 Num.10

10 **Tillert, T et al.** Estimating the U.S. prevalence of chronic obstructive pulmonary disease using pre- and post-bronchodilator spirometry: the National Health and Nutrition Examination Survey (NHANES) 2007–2010. http://respiratory-research.com/content/14/1/103

11 Health at a Glance 2011: OECD Indicators, www.oecd.org/els/health-systems/49105858.pdf

12 **AIHW 2012.** Australia's health 2012. Australia's health no. 13. Cat. no. AUS 156. Canberra: AIHW.

13 **Toelle B, Xuan W, Bird T, Abramson M, Burton D, Hunter M, Johns D, Maguire G, Wood-Baker R, Marks G.** COPD in the Australian burden of lung disease (BOLD) study. Respirology 2011;16 (Suppl 1):12

14 **Page A, Abrose S, Glover J et al.** Atlas of Avoidable Hospitalisations in Australia: ambulatory care-sensitive conditions. Adelaide PHIDU. University of Adelaide. 2007

15 Access Economics (2008); Economic impact of COPD and cost effective solutions; Report for The Australian Lung Foundation, October 2008

16 **Lungeninformationsdienst.** Wie verbreitet ist die COPD? http://www.lungeninformationsdienst.de/krankheiten/copd/verbreitung/index.html (Accessed February 2015)

17 http://www.medica.de/cipp/md_medica/custom/pub/content,oid,3829/lang,1/ticket,g_u_e_s_t/mcat_id,7807/local_lang,1 (Accessed February 2015)

18 **Lungenaerzte im netz.** COPD / Kosten. http://www.lungenaerzte-im-netz.de/lin/show.php3?id=36&nodeid= (Accessed February 2015)

19 **Deutsche Atemwegsliga e.V.** Was ist COPD http://www.atemwegsliga.de/copd.html?file=tl_files/copd/COPD-Leitlinie.pdf (Accessed February 2015)

20 **Staeck, F.** COPD und Asthma sind teuer. Ärzte Zeitung, 02.01.2015 http://www.aerztezeitung.de/politik_gesellschaft/versorgungsforschung/article/874700/hoher-versorgungsaufwand-copd-asthma-teuer.html (Accessed February 2015)

21 **The Asthma Foundation (2012).** COPD in New Zealand.

22 **The Asthma and Respiratory Foundation of New Zealand (2011)**. Literature Review: Respiratory Health for Maori.

23 Spanish Health Ministry Data

24 **Miravitlles M.,Soriano J.B.,García-Río R., Muñoz L., Durán-Tauleria E., Sánchez G., et al. (2009).** Prevalence of COPD in Spain: impact of undiagnosed COPD on quality of life and daily life activities. Thorax 64:863–8.

25 **Comité de expertos de la SEPAR.** Impacto social y económico de la EPOC en España. Estudio macroeconómico. Ed. Bernard Krief. Madrid 1995.

26 **Department of Health.** An Outcomes Strategy for Chronic Obstructive Pulmonary Disease (COPD) and Asthma in England (2011). https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216139/dh_128428.pdf (Accessed February 2015)

27 **British Lung Foundation.** Invisible Lives (2007) www.blf.org.uk/Files/94ff4ae1-1858-485f.../Invisible-Lives-report.pdf (Accessed February 2015)

28 **Centers for Disease Control and Prevention.** National Center for Health Statistics. National Health Interview Survey Raw Data, 2011. Analysis performed by the American Lung Association Research and Health Education Division using SPSS and SUDAAN software.

29 **Centers for Disease Control and Prevention.** National Center for Health Statistics. National Vital Statistics Report. http://www.cdc.gov/nchs/data/nvsr/nvsr61/nvsr61_04.pdf" Deaths: Final Data for 2010. May 2013; 61(04) (Accessed February 2015)

30 **Confronting COPD in America, 2000.** Schulman, Ronca and Bucuvalas, Inc. (SRBI) Funded by Glaxo Smith Kline.

31 **Walsh, J.** COPD Unmet Needs Assessment. Survey at ICC workshop, Munich, 2006.

32 **Thomashow, B M.** The COPD Foundation: Celebrating a decade of progress and looking ahead to a cure.

33 **GSK Press Release (November 11, 2014).** GSK survey points to rise of COPD in US.

34 **Patalano, F.** Addressing unmet needs in the treatment of COPD. European Respiratory Review, September 1, 2014. Vol. 23. No. 133. Pp 333-344.

35 **Lau, R, Bernard J.M. and Hartman, K.A. (1989).** Further explorations of common sense representations of common illness. Health Psychology, 8, 195-219.

36 **Skelton, J.A. and Croyle, R.T. (1991)** (Eds). Mental Representation in Health and Illness. New York: Springer-Verlag.

37 **Fischer, M. et al (November 2010).** The dynamics of illness perceptions: Testing assumptions of Leventhal's common-sense model in a pulmonary rehabilitation setting. British Journal of Health Psychology (2010), 15, 887–903.

38 **Van Beerendonk I, et al. (1998).** Assessment of the inhalation technique in outpatients with asthma or chronic obstructive pulmonary disease using a metered-dose inhaler or dry powder device. J Asthma, 35:273–79.

39 **Gruffydd-Jones, K (December 2014).** Asthma and COPD patient adherence: the right inhaler.

40 www.copdfoundation.org/Global-Patient-Leadership-Summit.aspx#sthash.TTtpgio8.dpuf. (Accessed February 2015)

41 **Woods. P.** The unmet needs of respiratory patients. May 12, 2014.

42 **Covvey, JR et al.** A comparison of medication adherence/persistence for asthma and chronic obstructive pulmonary disease in the United Kingdom. International Journal of Clinical Practice.

43 **George J. et al. (2005).** Factors associated with medication non-adherence in patients with COPD. Chest, 128:3198–204.

44 **Turner J. et al. (1995).** Predictors of patient adherence to long-term home nebulizer therapy for COPD. The IPPB Study Group. Intermittent Positive Pressure Breathing. Chest, 108:394–400.

45 **Incalzi RA, Pedoen C, Onder G, et al.** (2001) Predicting length of stay of older patients with exacerbated COPD. Aging, 13:49–57.

46 **Fenerty, S. D. et al. (2012).** The effect of reminder systems on patients' adherence to treatment. Patient Preference and Adherence, 6, 127-135.

47 **Krebs, P. et al. (2010).** A meta-analysis of computer-tailored interventions for health behaviour change. Preventive Medicine, 52, 214-221.

48 **Bender, B. G. et al. (2010).** Test of an interactive voice response intervention to improve adherence to controller medication in adults with asthma. J Am Board Fam Med. 23, 159-165.

49 **Charles, T., Quinn, D., Weatherhall, M., Aldington, S., Beasley, R. & Holt, S. (2007).** Journal of Allergy and Clinical Immunology, 119, 811-816.

50 **Goldman, R. E. et al. (2008).** Developing an automated speech-recognition telephone diabetes intervention. International Journal for Quality in Health Care, 20(4), 264-270.

51 **Kaptein, A. A. et al. (2009).** 50 years of psychological research on patients with COPD – Road to ruin or highway to heaven? Respiratory Medicine, 103 (1), 3-11.

52 **Polisena, J. et al. (2010).** Home telehealth for chronic obstructive pulmonary disease: a systematic review and meta-analysis. Journal of Telemedicine & Telecare, 16 (3), 120-127.

53 Treatments for COPD cost the state 3,000 million euros a year. JANO.es. (November 12, 2012).

54 **Partners in Delivery:** Working in partnership with industry to support the implementation of the Outcomes Strategy for COPD and asthma.

55 **Levack W, Weatherall M, Reeve J et al**. Uptake of pulmonary rehabilitation in New Zealand by people with chronic obstructive pulmonary disease in 2009. NZMJ 2012;125:23-33

56 http://www.prnewswire.com/news-releases/copd-drug-market-opportunity-and-clinical-pipeline-analysis-255851781.html (Accessed February 2015)

57 **Press Release (October 9, 2012).** Decision Resources.

58 **Taylor, L (March 21, 2014)** Patients 'want and expect' health management help from pharma: study. http://www.pharmatimes.com/article/14-03-21/Patients_want_and_expect_health_management_help_from_pharma_study.aspx (Accessed February 2015)

59 **Press Release (December 18, 2014).** Aseptika