

<b>Institution: Manchester Metropolitan University</b>		
<b>Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy</b>		
<b>Title of case study: Improving standards, services and support for people with COPD</b>		
<b>Period when the underpinning research was undertaken: 2000-2017</b>		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Abebaw Yohannes	Professor	1993-2017
Juliet Goldbart	Professor	1980-present
Francis Fatoye	Professor	2006-present
<b>Period when the claimed impact occurred: 1 August 2013 - 31 December 2020</b>		
<b>Is this case study continued from a case study submitted in 2014? No</b>		
<p><b>1. Summary of the impact</b></p> <p>Two decades of our research into the experiences of people living with Chronic Obstructive Pulmonary Disease (COPD) have helped healthcare professionals and regulators to understand and treat this under-served patient group. Research on anxiety and depression underpinned consensus statements in every iteration of the NICE guideline on COPD, informing practice across England and Wales. Research is used as evidence in the Scottish National COPD Best Practice Guidance, the Global Obstructive Lung Disease (GOLD) guideline on COPD and the World Health Organisation (WHO)'s Essential Medicine List. It also shaped recommendations in British Thoracic Society guidance on Pulmonary Rehabilitation and home oxygen use. Through these evidence-based standards, our research has supported clinicians to manage exacerbations, improve services and enhance the quality of life of COPD patients worldwide.</p>		
<p><b>2. Underpinning research</b></p> <p>Professor Abebaw Yohannes' research investigates the factors that shape the outcomes and quality of life of people with chronic diseases, with a particular focus on improving the knowledge base on COPD. With colleagues, he identified the high prevalence of (often untreated) depression and anxiety in patients with COPD. His research collaborations have also provided insights into the lived experiences of this under-served group, helping healthcare professionals to establish treatment options. Yohannes became a lecturer at the Manchester School of Physiotherapy in 1993 and a Research Fellow in 1999, where he was part of a team that established the service-led pulmonary rehabilitation (PR) programme at Manchester Royal Infirmary (led by Dr. Martin Connolly). He lectured at Manchester Metropolitan alongside this work from 2001 and moved to the University full-time when the two institutions merged in 2014 (<i>we have received prior agreement from Research England to submit this case study from Manchester Metropolitan</i>).</p> <p>In 2000, Connolly, Winn, Roomi and Yohannes designed and validated the <b>Manchester Respiratory Activities of Daily Living (MRADL)</b> scale to quantify disability in COPD patients. Prior to this, there was no respiratory-specific ADL scale for use in older patients. Their study showed that the MRADL was reliable in this subject group, discriminated well between older COPD and normal controls, and was responsive to PR [1]. Connolly, Greenwood and Yohannes also validated the MRADL for use as a <a href="#">postal questionnaire</a> with elderly patients with COPD (2002). They compared face-to-face administration by a physiotherapist with postal completion in two single-blind studies to determine its test-retest reliability and concluded that it was acceptable and repeatable in this subject group. Maurici, Yohannes, Reis, Fleig Mayer and Junkes-Cunha later (2016) translated the MRADL scale <a href="#">into Portuguese</a> to create a version that was suitable for use in Brazil. Yohannes also led a <a href="#">national representative survey</a> (2004) that addressed a lack of data on the availability of PR programmes in the UK. It revealed that 40% of the hospitals surveyed ran a PR programme. Despite the high prevalence of COPD-related disability in old age and evidence that PR can improve quality of life and exercise capacity for this patient group, the programmes largely focused on younger subjects. Suggesting that this may reflect a lack of referrals, the findings indicated the need for greater awareness and availability of PR. This work informed a <a href="#">subsequent audit of PR programmes</a> against national standards (2011), providing further insights.</p> <p>Whilst symptoms of <b>depression and anxiety</b> are common in elderly patients with COPD, there was also a lack of data about the true prevalence of clinical depression and anxiety. Connolly, Baldwin and Yohannes (2000) used the Geriatric Mental State Schedule (GMS) and the Montgomery Asberg Depression Rating Scale (MADRS) to assess this subject group. They concluded that clinical depression and anxiety were common (of those depressed, two-thirds</p>		

scored in the moderately depressed range) but that clinical anxiety seemed to be mainly confined to those who also suffered clinical depression. They also validated the Brief Assessment Schedule Depression Cards (BASDEC) screening test for depressive symptoms against the GMS for use in this patient group [2].

The researchers set out to evaluate **predictors of mortality** in the same patient group, collecting baseline data on 137 outpatients aged 60-89 with symptomatic disabling COPD (2002). Subjects completed the MRADL, BASDEC, the Breathing Problems Questionnaire (which measured quality of life) and the MADRS. They were followed, and survival and mortality data were confirmed, through general practitioners and hospital notes at 30 months. They found disability, use of long-term oxygen therapy, pre-bronchodilator lung function and body-mass index were independent predictors of mortality in elderly patients with severe COPD [3].

Addressing a further gap in evidence on **comorbid anxiety**, PhD student Willgoss and Yohannes (2012) performed a [systematic review](#) of studies that report the prevalence of clinical anxiety and specific anxiety disorders in patients with COPD, searching articles in CINAHL, EMBASE, MEDLINE and PsycINFO (1966-2012). They found the prevalence of clinical anxiety ranged from 10%-55% among in-patients and 13%-46% among out-patients with COPD, and the reported prevalence of specific anxiety disorders ranged considerably. They concluded that there was a high prevalence of clinical anxiety in patients with COPD, particularly social phobia and specific phobia, and recommended further research into effective management and screening for clinical anxiety disorders [4]. Observing that existing anxiety measures contained somatic items that can overlap with symptoms of COPD and side effects of medications, they developed and validated a disease-specific, non-somatic scale with colleagues, Fatoye and Goldbart. The study demonstrated that the scale – the **Anxiety Inventory for Respiratory Disease (AIR)** – was user-friendly, reliable and valid for measuring and screening anxiety in patients with COPD [5].

In 2013, NHS Wirral commissioned Yohannes, Goldbart and Woolrych to appraise the levels of satisfaction of patients with COPD after receiving **long-term oxygen therapy (LTOT)** as part of a larger evaluation of its services. They used semi-structured interviews and focus groups to explore experiences of COPD-related health services from the perspectives of COPD patients, their carers and the healthcare professionals who deliver these services. They reported benefits including increased social activity, perceived improvements in health status and self-management in routine daily activities. However, they also highlighted concerns around stigma, dependency and deterioration. The research indicated that multidisciplinary care team follow-up may have contributed to the high levels of satisfaction (88%) and suggested increased support and monitoring, and better information may maximise patient benefit [6].

Extending their research to drug treatments, Yohannes, Willgoss and Vestbo also conducted a systematic review of recent evidence on the **effectiveness of tiotropium** versus placebo, ipratropium, and long-acting  $\beta(2)$  agonists on outcomes relevant to patients with stable COPD. Using St George's Respiratory Questionnaire, they found tiotropium showed superior efficacy in improving quality of life and dyspnea in stable COPD, compared to placebo and ipratropium. However, tiotropium's differences with salmeterol were less clear [7].

### 3. References to the research

- [1] **Yohannes** AM, Roomi J, Winn S *et al*. The Manchester Respiratory Activities of Daily Living questionnaire: development, reliability, validity, and responsiveness to pulmonary rehabilitation. *Journal of the American Geriatrics Society*. 2000; 48(11):1496-1500. DOI: [10.1111/jgs.2000.48.11.1496](#), Citations: *Web of Science* 48 (expected 72.96).
- [2] **Yohannes** AM, Baldwin RC, Connolly MJ. Depression and anxiety in elderly outpatients with chronic obstructive pulmonary disease: Prevalence, and validation of the BASDEC screening questionnaire. *International Journal of Geriatric Psychiatry*. 2000; 15(12):1090-1096. DOI: [10.1002/1099-1166](#) Citations: *Web of Science* 186 (expected 50.03).
- [3] **Yohannes** AM, Baldwin RC, Connolly M. Mortality predictors in disabling chronic obstructive pulmonary disease in old age. *Age & Ageing*. 2002; 31(2):137-140. DOI: [10.1093/ageing/31.2.137](#)
- [4] Willgoss TG & **Yohannes** AM. (2013) Anxiety disorders in patients with COPD: a systematic review. *Respir. Care*; 58(5): 858-66. DOI: [10.4187/respcare.01862](#)
- [5] Willgoss, TG, **Goldbart**, J, **Fatoye**, F, **Yohannes**, AM, The Development and Validation of the Anxiety Inventory for Respiratory Disease. *Chest*. 2013; 144 (5): 1587-1596. DOI: [10.1378/chest.13-0168](#)

[6] **Goldbart J, Yohannes AM, Woolrych R, et al.** 'It is not going to change his life but it has picked him up': a qualitative study of perspectives on long term oxygen therapy for people with chronic obstructive pulmonary disease. *Health Qual Life Outcomes* 2013;11:124.

DOI: [10.1186/1477-7525-11-124](https://doi.org/10.1186/1477-7525-11-124)

[7] **Yohannes AM, Willgoss TG, Vestbo J.** Tiotropium for treatment of stable COPD: a meta-analysis of clinically relevant outcomes. *Respir. Care.* 2011;56(4):477–87. DOI:

[10.4187/respcare.00852](https://doi.org/10.4187/respcare.00852)

#### Funding

G1. Yohannes, AM, Connolly, M (PIs), Roomi, J and Baldwin, R, Clinical depression and hospital admission for acute exacerbations of COPD in elderly patients, National Health Service, Research and Development, 1999-2001, GBP76,000.

G2. Yohannes, AM (PI), Goldbart, J, An evaluation of service delivery of patients with COPD receiving long term oxygen therapy and attending the primary care assessment unit, NHS Wirral, 2010-11, GBP28,600.

#### 4. Details of the impact

COPD is a leading cause of disability, healthcare utilisation and mortality in old age. An estimated 3,000,000 people in Britain (BLF, 2012) and 210,000,000 worldwide (World Health Organisation) are living with the disease. 65,000,000 people have moderate to severe COPD (GOLD 2019). With no known 'cure', it was long felt that little could be done to help patients. However, since the 1990s, new research and treatment options have led to a focus on managing the disease, reducing exacerbations and optimising lung health. Highlighting gaps in provision and opportunities to improve care, Yohannes' research is a critical part of the evidence base for guidelines and practices that have improved the quality of life of COPD patients.

The debilitating symptoms of COPD can lead to social isolation and the development of depression and anxiety. The conditions may also co-exist. Although they worsen a patient's quality of life and ability to cope, they are often overlooked due to the overlap with symptoms of the disease. The **first ever NICE guideline** on the management of COPD in adults in primary and secondary care (CG12, 2004) began to address this by including guidance on identifying and managing anxiety and depression. Yohannes' studies (2000-2002) on mortality predictors, depression and anxiety, anti-depressant therapy and the MRADL and BASDEC scales were central to the evidence base for this section. They constituted five of the 16 studies cited (in addition to two of his earlier studies), informing the consensus statements. NICE retained guidance, based on his research, in subsequent iterations (CG101 2010, NG115 2018), which inform patient care across England and Wales to the present day. The Chair of the Guideline Development Group stressed that these earlier recommendations remain: *"just as important and relevant now as they did when the original guideline was produced"*. Underscoring this, the 2014 surveillance review of the guideline cited Willgoss and Yohannes' systematic review of anxiety disorders in patients with COPD (2013) as evidence that its existing recommendations were still valid. NICE also drew on Yohannes *et al.*'s [longitudinal follow-up study](#) (2017) on the association of depressive symptoms with rates of acute exacerbations in patients with COPD in a major evidence review focused on predicting and preventing exacerbations (2018). **[A]**

Internationally, Yohannes' findings on COPD mortality rates and the multifactorial causes of depression and anxiety informed the recommendations made on the management of stable COPD, and prevention and maintenance therapy in all versions of the annual **Global Obstructive Lung Disease (GOLD)** guidelines from 2017-2020. His research on the benefits of walking aids is also used as evidence in a section on PR therapy in all earlier GOLD guidelines from 2013-2016. Launched in 1997, in collaboration with the National Heart, Lung and Blood Institute; National Institutes of Health, USA; and the World Health Organization, GOLD aims to: *"Recommend effective COPD management and prevention strategies for use in all countries"*. **[B]**

At strategic-level, Yohannes' research on depression and COPD informed the UK's **Chief Medical Officer's** annual report (2013) 'Public Mental Health Priorities: Investing in the Evidence.' It was used to evidence depression levels amongst COPD patients and demonstrate that people with COPD, who also have co-existing depression and anxiety, have higher functional disability, greater loss of productivity and greater health resource use. The advocacy volume led to 14 recommendations, including that all Health and Wellbeing Boards should have a focus on mental health in the Joint Service Needs Assessment (JSNAs), and ensure mental health needs receive 'parity of esteem' or equal priority with physical healthcare. **[C]**



In 2017, the **Scottish Government** launched its COPD Best Practice guidance in response to national data that showed COPD was the most common cause of presentation to Emergency Departments (ED) with a respiratory emergency, and that figures were rising. The guidance profiled three case studies, including one on Integrated Care in NHS Lothian. This used Yohannes and Willgoss' research on anxiety to highlight how the relationship between hyperventilation and symptoms can lead to unnecessary 999 calls, and evidenced the prevalence of anxiety and depression in people with COPD. It describes the recognition of this '*significant unmet need*' as one of the drivers to the programme and one that was critical to its success. The psychological interventions that NHS Lothian delivered as a result led to '*a clinically significant improvement*' in patients' quality of life. The support also contributed to a 7% reduction in stays of 48 hours or less and a reduction in respiratory bed days that exceeded its target by over 500% (April 2013-September 2015). The national COPD working group drew on the case studies and associated evidence to design a series of best practice recommendations, including '*Access to psychological therapies and assessment of psychological distress to reduce anxiety and improve mood and coping skills*' and '*dedicated psychology input*.' The project also informed the development of an Anticipatory Care Plan (ACP) that included psychological needs alongside others and shaped a programme to support nationwide implementation. [D]

**Public Health England (PHE)** cited Yohannes' COPD research in its 'State of Respiratory Health in Yorkshire and the Humber' (2019). Again, his findings on COPD and depression in elderly outpatients with COPD supported a claim that, "*anxiety is a significant predictor for hospital admissions as symptoms continue to be unrecognised and untreated in COPD patients*". His findings on palliative care in patients with COPD were also used to demonstrate that "*people with advanced stage disease are much less likely to access palliative care compared to people with cancer*", and address the factors influencing poor quality end-of-life care for this group. PHE invited health and social care commissioners; providers and professionals in the region, where COPD was also responsible for 13.6% of all deaths in 2017, to "*use the resource to review best practice, identify key areas of current delivery and address areas for improvement*". [E]

Growing attention to non-medical support for COPD patients has led to a focus on the benefits of PR services. The **British Thoracic Society (BTS)** used Yohannes' findings on the marked variation in PR services across the UK to demonstrate the need for the first evidence-based national Guideline for Pulmonary Rehabilitation (2013). The guideline provided the rationale for its Quality Standards (2014) and formed the basis of the Royal College of Physicians' Accreditation scheme (2018), which aims to drive further quality improvement in PR. The Joint BTS/Association of Chartered Physiotherapists (ACPRC) Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient (2009) also cite Yohannes and Connolly's research on [early mobilization with walking aids following hospital admission](#) (2003). It is the sole piece of evidence used to support its recommendation that practitioners: "*Assess the effectiveness of a gutter rollator frame in the acute setting, for patients with COPD severely disabled by breathlessness, especially the elderly*". The research found that using those frames greatly facilitated ambulation – a benefit the guideline extends to patients to the present day. [F]

Further informing practice, in 2013, Yohannes was one of 163 national experts who took part in a Delphi process led by the **European Respiratory Society (ERS)**'s Respiratory Physiotherapy Harmonised Education in Respiratory Medicine for European Specialists (HERMES) task force. This shaped the development of a [consensus-based international syllabus in respiratory physiotherapy](#) (adult and paediatric tracks) to "*serve as a blueprint for organisations that engage in the development of postgraduate education in respiratory physiotherapy*" and, in 2019, [a curriculum](#). The **American Respiratory Society (ARS)/ERS** cite five of Yohannes' papers on PR and COPD (2000-2011) in the current joint statement on Key Concepts and Advances in Pulmonary Rehabilitation (2013), which "*represents the consensus of 46 international experts in the field of pulmonary rehabilitation*". His research informed the expert's case that "*recognition of comorbidities is essential because treating them can have a beneficial effect on COPD and vice versa, and early intervention may actually influence the course and prognosis of the disease*". [G]

As both MRADL and AIR are sensitive to change following PR, health professionals can use them to evaluate the effectiveness of interventions. The ARS/ERS statement confirms that MRADL is "*commonly employed*" for this purpose. It is also one of three tools the current **NICE guideline** on the management of COPD in adult states: "*can be used to formally assess patients' need for occupational therapy*". MRADL has been used in clinical PR research in UK hospitals,

translated for use in hospitals in China, which has the world's highest prevalence of COPD, and validated for use in Hong Kong. Additionally, health professionals in New Zealand have highlighted its potential in determining which patients may benefit from a palliative approach to care. AIR has been used in clinical interventions in the USA and Canada, and translated and validated for use in China and Brazil. Willgoss has also transferred methodological approaches from the development of AIR to his role as Head of Head of Clinical Outcome Assessments (Europe) at pharmaceutical company, Roche, informing outcome measures his team uses to assess concepts relevant to patients. [H]

Yohannes and Goldbart's research into LTOT for people with COPD helped **NHS Wirral** to improve service delivery in line with patient needs. Despite the challenges posed by Covid-19, the Trust has retained and enhanced some of the services that the study showed were valued. These include specialist home oxygen and community-based PR. The report Yohannes and Goldbart produced also recommended better communication between the Hospital Admissions Prevention Service (APS) and the Community teams, plus the introduction of a 24-hour service. NHS Wirral implemented these changes in 2012, fully integrating the APS into a 24-hour integrated Community Nursing Service, which is still in place today. Their conclusions about the importance of education from specialist nurses or physiotherapists also informed recommendations on the follow-up of LTOT patients in the BTS guidance on home oxygen use (2015). [I]

The **WHO Expert Committee on Selection and Use of Essential Medicines** (2019) cited Yohannes, Willgoss and Vestbo's findings on tiotropium as evidence of its efficacy in reducing COPD exacerbations. Concluding that it was also safe and cost-effective, it recommended the inclusion of tiotropium with a square box to the core list of the Essential Medical List (EML) for use in the treatment of COPD. It was one of twelve medicines added to the core EML list, which includes "*the most efficacious, safe and cost-effective medicines for priority conditions*" for "*minimum medicine needs for a basic health-care system*". More than 150 countries use the list to compile essential medicines lists that meet their own priorities. The list captures "*the medicines that need to be available in a functioning health system at all times, in appropriate dosage forms, of assured quality, and at prices individuals and the community can afford*". [J]

## 5. Sources to corroborate the impact

[A] i NICE, 'CG12: Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care,' 2004 (included in ii); ii NICE, '[CG101: Chronic obstructive pulmonary disease in over 16s: diagnosis and management](#)', 2010; iii NICE, '[NG115: Chronic obstructive pulmonary disease in over 16s: diagnosis and management](#)', 2018; iv NICE, '[CG101: Surveillance Report for GE \(post consultation\)](#)', July 2014; v NICE, '[\[E\] Predicting and preventing exacerbations \(NG115\)](#)', December 2018.

[B] Global Initiative for Chronic Obstructive Lung Disease (GOLD), [Global Strategy for Prevention, Diagnosis and Management of COPD reports](#), 2013-2020 (2013-16 on request).

[C] Prof. Dame Sally C Davies, [Annual Report of the Chief Medical Officer, 2013. Public Mental Health Priorities. Investing in the Evidence](#), Department of Health, September 2014.

[D] The Scottish Government, [COPD Best Practice Guide](#), 2017.

[E] Public Health England, [The State of Respiratory Health in Yorkshire and the Humber](#), 2019.

[F] i British Thoracic Society, Guideline for Pulmonary Rehabilitation, 2013; ii British Thoracic Society/Association of Chartered Physiotherapists, [Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient](#), 2009.

[G] i Troosters, T, *et al.* [Development of a syllabus for postgraduate respiratory physiotherapy education: the Respiratory Physiotherapy HERMES project](#), European Respiratory Journal 2015 45: 1221-1223; ii American Thoracic Society/European Respiratory Society, [Statement on Key Concepts and Advances in Pulmonary Rehabilitation](#), 2013.

[H] i Compiled guidance and papers citing use of MRADL/AIR; ii Testimonial, Head of Clinical Outcome Assessments (Europe), Roche.

[I] i Details of launch of community nursing service (January 2012) and Wirral NHS Foundation Trust [Community Nursing webpage](#); ii BTS, [Guidelines for Home Oxygen Use in Adults](#), 2015.

[J] i World Health Organisation (WHO), [The selection and use of essential medicines: report of the WHO Expert Committee on Selection and Use of Essential Medicines, 2019](#), WHO Technical Report Series 1021, 2019; ii World Health Organisation (WHO), [World Health Organisation Model List of Essential Medicines, 21<sup>st</sup> list](#), 2019.