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## Is a qualitative perspective missing from COPD guidelines?

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As researchers in the Centre for Medical Humanities we are interested in what the medical humanities and social sciences can contribute to the understanding and treatment of somatic illness. Our interest in the historical development of the disease entity known as COPD was born-out of ethnographic work carried out by the first author (MW) on COPD in Uruguay and is directed at future research on lay and medical concepts of the illness. We are interested in how, by widening our cultural—historical understandings of COPD, we may better interpret the clear evidence of a distinction between measured and experienced symptoms in this illness. To get to grips with how the current definition, treatment and management of COPD came to be, we decided to compare present and past national and international clinical guidelines.

In this Spotlight, we focus on a comparison of the GOLD and NICE guidelines. Both guidelines are freely available online and are comparable in terms of their depth and scope. We are interested both in intra-guideline trajectories, to examine how changes in thinking about COPD are reflected in the guideline through its new iterations, and also in inter-guideline differences. We make a number of observations about how these guidelines differ in the composition of their expert teams, and how they are similar in their exclusion of certain kinds of questions and evidence.

### Guideline Goals and Audience

Full guidelines are extensive reports (90+ pages GOLD, 673 pages NICE) which include the literature on which recommendations are based. From these, concise guidelines for use in clinical settings and patient guides are created. We looked at all versions of guidelines, but particularly at ‘Full’ guidelines for their methodology sections.

When GOLD released its first guidelines in 2001, it described its audience as ‘pulmonary specialists and other interested physicians’ (GOLD, 2013, xiii) while after 2009, guidelines were redesigned to ‘reach target audiences – the general practitioner and the individuals in clinics...’ (xiv). Their more concise *Pocket Guidelines* are intended for ‘Health Care Professionals’ in general. NICE’s audience includes, among others, ‘all healthcare professionals’ and ‘people with COPD and their carers’ (32). Although intended ‘for all’ we wondered: who are being invited to participate in their production?

## Who is Asking What Questions and Reviewing What Literature?

While GOLD states that their guideline team is made up of ‘individuals with expertise in COPD Research and patient care’ (xiii), not a single member of the Board of Directors or Science Committee is a nurse, physiotherapist or other allied health professional – professionals whom few would disagree hold a wealth of expertise in COPD research and patient care. Non-clinician social scientists are also not included. NICE’s Guideline Development Group (GDG) is far more multidisciplinary including members from nursing, nutrition, physiotherapy, and patient and carer groups.

With this committee composition in place, we found it unsurprising that the GOLD guideline limited their evidence search to PubMed and clinical trials. It is unlikely that a committee made up only of physicians would have the expertise needed to evaluate qualitative research; and this lack of multi-disciplinarity would seriously limit the kinds of questions the guidelines would seek to answer. GOLD does however have a health economist involved in the review process as does NICE. There was only one explicitly qualitative research article we could find in the GOLD bibliography, but we are aware from our work that there are at least fifty qualitative research articles published in the past 15 years on the experience of COPD.

The NICE guideline is, in theory, inclusive of different kinds of evidence and purports that it is the ‘first to systematically bring together and examine all the evidence in the published literature’ (18). It explicitly states in the review protocol that ‘Searches should not necessarily be restricted to RCTs’ (37) and a NICE guideline is available on how to assess qualitative studies (NICE, 2007, Appendix H; see also Davies & Dodd, 2002). They also look beyond PubMed to Embase. However, both GOLD and NICE equally exclude the Cumulative Index to Nursing and Allied Health Literature (CINAHL) as an evidence database.

NICE literature searches are driven by “a series of clinical questions that covered the guideline scope” (26). Interestingly it is not the GDG that drafts these but rather the technical team which is far less interdisciplinary and includes: an information scientist, a systematic reviewer, a lead clinical advisor (a physician) and a health economist (531). The GDG meets to discuss, refine and approve these questions (532) but not to propose alternative questions. This is potentially the greatest unrecognised source of bias in both the GOLD and NICE guidelines; The range of questions posed are from the outset limited because those with the power to ask them come from a limited pool of perspectives and expertise.

Some questions posed by the NICE technical team allow all kinds evidence (including qualitative) to be searched and assessed and others not. ‘All types of studies’ were included to address questions about self-management, support and education needs and end-stage management. We also feel that other questions could be partly answered on the basis of qualitative research such as ‘How are patients with stable COPD affected by anxiety and / or depression?’ (Q67, p. 419). Surprisingly, despite NICE’s seemingly inclusive policy, in reviewing reference lists we found little difference between GOLD and NICE. For example,

we found only one study published in a nursing journal in each bibliography and no publications from social science journals.

Why is this? As external observers to this process we can only speculate, but it seems likely that a too strict interpretation of the hierarchy of evidence is, first, restricting the range of possible questions being asked in the guidelines, and, second, is leading to the exclusion of evidence generated by different research paradigms. This is important, especially in view of the fact that ‘all health professionals’ and ‘patients’ are the target audience of guidelines and it is necessary that the questions they ask are taken into account. In the final section of this essay/Spotlight, we suggest four topics which from our perspective are important and require a multi-disciplinary approach to assessing the literature.

### Scope: Cultural-Factors

The question ‘Do cultural factors modify the uptake of COPD care?’(430) was initially included in NICE but subsequently removed because it was considered ‘outside of Scope’. It is unclear how ‘scope’ is defined and who defines it. What strikes us about this question is how it is framed. Cultural factors are, it seems, of interest only insofar as they relate to doctors accessing patients for clinical review. From our perspective, an important prior question is ‘how do cultural factors shape the *experience* of COPD or its symptoms’? Research in Uruguay found that shared health beliefs about the adverse effects on breathing of atmospheric humidity shaped how people interpreted changes in breathing and led to certain social practices to avoid these effects (sometimes conflicting with health professionals’ indications – non-attendance at appointments on humid days for example).

### Scope: Service Delivery

Service delivery is not currently considered a guideline issue. But we know that positive outcomes for the patient are determined not only by *what* health professionals deliver, but *how* they deliver it. Providing the patient with the best information and medication is only one part of the equation, the other is how the patient perceives the health professionals, interprets the information, compares it with their own knowledge (and that of trusted others), and makes a decision. The qualitative literature often explores the murkiness of patient experience by letting people express themselves in their own terms and by observing their behaviours outside of clinical contexts. For example, work in Uruguay suggested that oxygen-use could be subtly shaped by family members and patients’ ideas that using home-oxygen for fewer hours was a sign of recovery. Clearly, understanding individuals and family members’ subjective experiences of the disease and oxygen-use is fundamental for improving and monitoring whether the treatments proven to prolong life are being used the way they had been in clinical trials.

### Scope: Symptoms

In the guidelines one can see the rise and fall of the supremacy of spirometric lung function values as the defining measurement of severity. While there is now consensus that spirometry is necessary to confirm a diagnosis of COPD, there is an increasing ‘emphasis on the clinical features of the disease and not over-reliance on spirometry’ (NICE 2010, 20).

The GOLD guidelines' Combined Assessment of COPD includes lung function data, exacerbation history and symptoms. Symptoms are reduced to mMRC or CAT scores which are predominantly about physical function. Within the cultural-literary record on breathlessness and the qualitative research on COPD one encounters a far more complex perspective on how symptoms are understood by patients. In Michael Symmonds Roberts' novel *Breath*, the lung disease patient awaiting a transplant asks, 'Are the lungs pulling and pushing the air, or is the air working him like an old pair of bellows?' Characteristics of air seem especially important in patients' experience of symptoms (see Williams et al., 2011)

## Scope: Patient-Voice

Implicit in the NICE guidelines is the importance of including patients and family members as stakeholders in the production of guidelines. This is a crucial inclusion (which is not yet part of GOLD's approach), but there seems to be a missed opportunity here in that these 'experts by experience' were not involved in defining the NICE questions of the guidelines. Particularly surprising to us is that while the voices of one or two expert-patients or carers are given a forum in which to be heard (in the GDG), hundreds of patients voices presented verbatim in the qualitative literature are being silenced because the literature is either missed or ignored. This literature includes rich first-hand descriptions of symptoms, concerns, satisfaction (or otherwise) with care, and interpretations of medical information.

In summary, then, we reviewed two national and international guidelines on COPD to examine historical development of the disease category. What we discovered was a contradiction between who the guidelines are for and who has the power and influence to define their scope and the evidence-base from which they are created. The idea that medical knowledge is in part socially constructed is not new (see Young, 1981), yet this essay illustrates how the assumptions which underlie the inclusion and exclusion of evidence and expertise continue to be insufficiently questioned in the social spaces of guideline production (e.g. committees) which in turn shapes their content.

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