Covid and Society: Accessing healthcare before, during and after the pandemic

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In April 2019, at the height of the coronavirus pandemic, the U.K. was at risk of not being able to meet the healthcare needs of its population. Strict measures were put in place to restrict social contact in order to prevent the spread of the virus and relieve pressure on the NHS. The measures were effective although it was recognised that such measures would need to be re-introduced if infections rose too rapidly again, leading to an increase in hospital admissions and deaths. Testing and contact tracing has since increased together with improved ways to treat the disease. However, as we come through the worst of the pandemic and move towards the mass provision of vaccines much is still unknown about the long-term health effects of COVID-19 infection and the consequences of these for society.

This position paper is an attempt to reflect on what we have learned from responses to Covid-19 by the healthcare sector, the research community and patient groups, and to understand what could usefully be learned about the configuration of collaborative working between these three sectors that could improve trust in medicine and science and better serve society in the aftermath of the pandemic. We look at the ways in which the pandemic increased social awareness of lesser known 'invisible' disabilities that patients have suffered from with little help or understanding. We take olfactory dysfunction (anosmia and parosmia) as a case study, with comparison to Functional Neurological Disorder, as examples where chronic symptoms (smell loss, fatigue) suddenly became acute during the coronavirus outbreak, drawing increased attention from the public, from healthcare services and from scientific researchers.

This change has galvanized patient advocacy groups to play a greater role in conveying reliable information, including the results of the most recent scientific research not just to patients but also to GPs and other healthcare workers. The role and constitution of such patient groups, including support from medical and scientific researchers, could play a vital role in maintaining a high level of public trust and confidence in medicine and science. Consideration is given to how the health and well-being of patients with 'invisible' disabilities have often been neglected, how this affected both the recognition and response to their condition during the pandemic and may affect its recognition in the post-pandemic response to Long Covid. Patient groups have received a boost in support from the public seeking information about their symptoms and as a matter of public policy, thought should be given to the best way to coordinate the increasingly collaborative efforts patient groups, healthcare services and researchers to improve health and wellbeing and the management of Long Covid. Health inequalities are also considered with stress on the need to increase the reach of information, care provision and support.

Section 1. Pre-COVID-19 Patient Experience

Even before the outbreak of the pandemic, healthcare professionals in the U.K. warned that they were under pressure due to increased demand on services from the public; and members of the public described lengthy delays in securing GP appointments, with some resorting to using emergency services at hospitals, thereby putting more stress on acute care.

A curiosity of the situation as described is a concomitant frustration felt by those who do access healthcare services.[1] In a recent study, it is estimated that as many as 40% of patients consulting their GP have persistent physical symptoms that remain undiagnosed and are not regarded as organic disease. Health professionals find it difficult to account for symptoms that do not fit standard models of illness.[2] Many patients have had the experience of attending a GP appointment with physical symptoms whose aetiology remains unclear, prompting referrals to secondary care where they account for up to 50% of referrals.[3] Having arrived here they may at best receive a diagnosis of exclusion, though often specialists are unable to diagnose and/or sufficiently manage the problem. This occurs in all specialisms, with the some of the most frequent presenting symptoms being chest pain, fatigue, dizziness, headaches, back pain and abdominal pain.[4] For some patients the problems will resolve themselves, for others the symptoms continue undiagnosed and untreated leading to distress, as well as personal and societal economic effects through workplace absenteeism, presenteeism and a reduction of confidence in health care services. Epidemiological studies suggest that up to 20% of the population have at least one persistent physical symptom with associated impairment.[5] This is an issue not only for patients but also for clinicians, with both parties reporting frustration with clinical encounters that do not follow the expected arc of identification of cause and prescription of cure. [6]

This dissatisfaction with the clinical encounter can be seen in other, clearly identifiable populations of patients, grouped by symptoms, who repeatedly stress their frustration at what is perceived to be a poor standard of care and management for their conditions. One such population is those who have suffered post-viral smell loss, or, indeed, olfactory dysfunction arising from any cause.

Until the pandemic brought about widespread recognition of loss of smell (hyposmia – reduced smell, anosmia – absent smell) and taste as symptoms of COVID-19, this group of patients had little or no support or access to specialist healthcare, despite describing their condition as debilitating and profoundly impacting their quality of life.

The long-term effects on quality of life in case of olfactory dysfunction can be profound, leading to depression in up to 40% of patients, in a way that is dose dependent.[7]

Smell loss has a profound impact on all areas of life, including: altered eating; appetite loss; weight change; loss of pleasure in food, eating and social engagement; altered intimacy and an altered relationship to self and others. People speak about feeling alienated from their own homes and even from their own bodies:

> The world is very blank. Or if not blank, shades of decay. I feel alien from myself. It's also kind of a loneliness in the world. Like a part of me is missing as I can no longer smell and experience the emotions of everyday basic living. Detached from normality. Lonely in my body. It's so hard to explain.[8]

> I've found that not smelling like 'myself' has had a great impact on me. I am so used to my own smell, that smelling something else is alien, I don't feel like I am me anymore. (ibd.)

Eating is often without pleasure since most of what we call flavour is contributed by smell and without it, food seems tasteless and unappetizing. There is a danger of not detecting spoiled foods past their 'use by' dates and of not being able to heed the smell of gas, burning or other environmental hazards. [9] Patient reports on altered feelings of intimacy are not uncommon:

> I can't smell my boyfriend's natural scent, which makes me feel more distant from him. Like he is a stranger. I used to feel comforted being able to smell him while cuddling. Worse is that his kisses taste really bad to me now, so I avoid that, but haven't told him because I don't want to hurt his feelings. Also I am constantly worried that I smell bad myself and it makes me very insecure. (ibid.)
>
> A lot of my maternal bonding feelings for my children are tied up with smell
> I'm single but avoiding dating as I can't judge my own body smell accurately, and can't imagine what anyone else smells like! so I'm preferring to avoid knowing (ibid.)

What is reported here by patients is often accompanied by a frustration that they feel unable to convey to others how profoundly their lives are affected by smell loss and how difficult they find it to convince healthcare workers that their predicament is important.

Prior to the pandemic, olfactory dysfunction was estimated to affect approximately 20% of the general adult population, making it more common than blindness or profound hearing loss [10], yet as an 'invisible' impairment, with more insidious, less obvious effects on environmental navigation, it has been often overlooked and dismissed by healthcare professionals and funding bodies. In 2017, keyword searches of the biomedical database 'PubMed' using the terms 'audition' and 'vision' resulted in 175,077 and 174,179 respectively. The term 'olfaction', however, produced just 23,349 results, reflecting an endemic neglect amongst the wider research community that translates into poorly understood disease pathophysiology, disease impact and limited treatment options. Moreover, translational and clinical neglect at best compounds feelings of isolation and frustration in sufferers, at worst breeds fractious doctor-patient relationships.

Unfortunately, such lack of understanding is not limited to general practitioners, but includes Ear, Nose and Throat specialists. Patients have written:

> My own ENT knows very little about anosmia and she also doesn't understand the devastating impact of the loss of smell. My eyes started to tear up when she told me that the loss may be permanent. She was surprised and said, "is something wrong?
>
> I never realised shrugs are a kind of medical diagnosis
>
> My consultant said: if you have to lose a sense, that's the best one to lose
>
> I lost my sense of smell after having the flu (recovery was complicated by chemotherapy at the time). Both my oncologist and ENT were bemused by my distress over my smell loss. They both implied that I had my priorities wrong, ie, I should be grieving over the loss of my breast, not my 'nose'. A counsellor even suggested my grief might be 'misdirected'. I remember replying quite tartly that: unlike my olfactory nerves, my breast could easily be reconstructed. It still angers me that they thought they were in a better position than me to judge my quality of life... and that my attitude was somehow wrong.

In responses from a previous study in 2013 [11]

> My doctor did not know such a symptom existed. He was stunned that this could happen and stuck a couple things like coffee under my nose to test me. […] When he found out it had a name, anosmia, he looked up possible causes in their computer and decided to send me to get an MRI and a CT scan [- which is of no clinical value in such cases.] He refused to send me to an ear nose throat specialist because “I cannot send you unless I first diagnose a condition they can treat, like sinusitis”. (subject 0012)
>
> I don't care as much ultimately about what the public awareness of this condition is; I'm resigned to anosmia being a joke for those who don't have it. I do wish that doctors took it more seriously. I have talked to too many doctors who did not believe that I cannot smell. […] One especially ignorant fellow just didn't believe that I'm unable to smell anything at all and treated me as if I were some hysterical female, telling me it was entirely psychosomatic. This needs to change, and this is why I've just spent the last 45 minutes pouring all this out for you. (subject 0004)
>
> My doctor first said “You're lucky! You won't have to smell the diapers!” When that upset me, he replied that loss of the sense of smell was “no big deal” and I would “probably get it back in a few weeks”. That was more than a month ago and there has been no improvement. It is more terrible than I could have imagined… (subject 0079)

Other subjects also report disappointing interactions with their doctors (subjects 0030, 0035, 0054, 0073, 0080, 0121, 0133, 0196, 0238, 0267, 0271, 0395, 0402, 0428, 0571, 0897, and 0942). Doctors told them that olfactory dysfunction is “a good thing to have” (subject 0423), that it “is not a sickness” (subject 0001), “just a psychological feeling” (subject 0043), or they treated the patient's complaint as “a trivial matter” (subject 0019).

In a 2014 study of patients [12], ENT consultant, Carl Philpott and patient Duncan Boak quote from their respondents:

> ‘One of the most depressing issues is the lack of concern by the medical profession. Getting help from GP and then being told by specialist that there was “nothing that could be done” and sent away to live the rest of your life missing one of your vital senses. If I had lost my hearing, sight, a limb or had been disfigured more help would have been given. More training should be given on this issue for GPs and especially ENT students, with more smell and taste clinics provided.’
>
> ‘I saw a consultant at my local clinic who said he’d never heard of the symptoms I have experienced over the last 20 years.’
>
> ‘Even a specialist from a large teaching hospital could give me no hope of any form of self or professional help I was just told it was something I had to live with’

These doctors are, hopefully, a small minority, with most handling complaints of olfactory impairments professionally and with compassion towards their patients. Such compassion aside, many patients' frustration is caused by perceived lack of treatment options and known paucity of supporting scientific research. Nevertheless, anecdotal reports of doctors who had never heard of a form of chronic sensory impairment that affects approximately one fifth of the population is indicative of a problem. The consequences of neglecting chronic health problems tend to show up elsewhere in the healthcare system in their impact on health and wellbeing and thereby further associated healthcare burden. For example, from the 496 respondents in the 2014 study, we see high rates of depression (43%) and anxiety (45%), impairment of eating experience (92%), isolation (57%), and relationship difficulties (54%). Women appear to have significantly more issues than men in terms of social and domestic dysfunction relating to olfactory loss ($P = 0.01$). Qualitative disorders also affected more than

1 in 5 members with parosmia (smell distortions) reported in 19% and phantosmia (smell hallucinations) in 24%.

A common theme is that patients have had to 'make a nuisance of themselves' in order to get the access to healthcare and support that they needed for their olfactory dysfunction. What is more, initial lack of support has led to an increase in healthcare utilisation. Where satisfactory support is not found within local services, some patients report the added financial burden of travel and/or private consultations. [13]

It is worth, at this stage, comparing the experiences and frustrations of this population with the healthcare system and lack of trust in the medical profession with the experience of patients classified as having Functional Neurological Disorder (FND or 'conversion disorder'). Mark Edwards, a consultant neurologist and specialist on FND who was interviewed for this paper points out that:

> FND is one of the commonest diagnoses made in neurology practice. It affects people of all ages, but is most often seen in people aged 30-50, about 70% of whom are women. FND is a disabling condition: quality of life and disability are similar to that seen in people with Parkinson's disease and Multiple Sclerosis, loss of employment and income are very common, and many people experience persistent symptoms. People with FND experience a range of symptoms including paralysis, seizure-like episodes, tremors, sensory loss, pain, fatigue and cognitive "fog".
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> People with FND occupy and uncomfortable "no man's land" between neurology and psychiatry with, historically, neither speciality taking much interest or responsibility. People with FND are trapped by societal dualism between brain and mind, mirrored in healthcare, so that they neither belong to the relative safety of physical illness nor the stigmatised but still legitimate area of mental illness. They are instead often in the realm of imagined illness, where the term "psychological" is used in a pejorative and inaccurate way to mean that the illness is fake.
>
> The UK has led an international explosion of interest in FND over the past decade or so amongst neurologists, psychiatrists, allied health professionals and neuroscientists. This renewed interest has seen major epidemiological studies, which have revealed the enormous scale and economic impact of FND and that misdiagnosis rates in modern times are very low, neurobiological studies which have resulted in a new understanding of the mechanism of FND and how that interacts with psychiatric illness and environmental stressors, new avenues for treatment with specific psychological and physiotherapy interventions and the development of patient organisations, providing a powerful voice for patient advocacy.

> Far from being “medically unexplained”, it would in fact be extraordinary if FND did *not* exist, given what we know about the way in which perceptual experience (of the body, of the world) and voluntary control of movement arise within the nervous system. FND is a paradigmatic disorder of embodiment, in other words a problem with the system that provides an interface between our conscious experience and the “automatic machinery” of the body. This gives rise to a situation where, despite maximal effort and will, a person may not be able to move their legs, even though the “basic wiring” allowing their legs to move is still operating normally. The same type of dysfunction can lead to loss of control over sensory experience (e.g. loss of sensation, disordered sensation such as pain, loss of vision) and cognitive experience (e.g. dissociation, loss of access to memory). These often very profound problems occur in the absence of abnormalities on investigations typically used to investigate neurological disorders, such as structural MRI scans. Thus patients are often told “your tests are normal”, without any explanation being given for how the system has gone wrong.

Neurologist Mahinda Yogarajah, also interviewed for this paper makes a similar point:

> Functional neurological disorders and symptoms remain the Cinderella subspecialty of neurology. Despite nearly one third of patients attending neurology clinics having functional symptoms, for many years these patients have been ignored, and worse still, health professionals and the public alike have implicitly questioned the validity of their symptoms. It is therefore not surprising, that our own research has shown that patients with functional symptoms experience significant problems in obtaining a diagnosis and accessing health services and treatment, compared to patients with other neurological disorders with similar levels of disability.

These expert opinions are supported by research demonstrating the clinical experience of patients with persistent physical symptoms and by stakeholder lead community work sponsored by the Academic Health Sciences Network in the North of England to look at patient and clinician experiences of working with PPS.[14] From a patient perspective we hear the stories like the following:

> I got sent to neurology and he sent me back to orthopaedics and orthopaedics were the ones that referred me to neurology in the first place because they said it wasn’t an orthopaedic problem. And then I went for a second opinion and she didn’t get my files so she couldn’t help me. And then even the mental health therapies, all these treatments, everything, they can’t give you a treatment without knowing what they're

> treating you for. So I went through 15 years of that: ‘just keep taking the painkillers, I’m sorry, there’s nothing that we can do’.
>
> Patient eventually diagnosed with Fibromyalgia

We also see the other side of the coin from physicians:

> Conditions like fibromyalgia don’t engender the same response from clinicians that a cancer diagnosis does. Even if you’ve got melanoma that’s well-controlled, people tend to be more sympathetic with you than if you’ve got COPD […] And then fibromyalgia and medically-unexplained symptoms is probably even lower […] So there’s definitely a pyramid that affects how….not ‘nice’ we are but I think it does affect clinician behaviour
>
> North East England GP

It is clear from the emerging patient reports on Long COVID that some of the above issues already exist in this patient group. We can apply some of the lessons learned from the FND and other persistent physical symptoms patients to our understating and management of some of the overlooked symptoms of COVID-19 and the emerging clinical picture of long COVID.

Section 2. Moving from Chronic to Acute Symptoms during COVID-19

It is instructive to consider what changed – and what didn’t – when symptoms seen in these chronic conditions turned up as acute symptoms in the midst of the coronavirus pandemic. How were symptoms viewed, how were patients treated and what kind of support was offered? A perspective on these responses can help to guide us in adjusting to what is needed in the future, after the pandemic.

COVID-19 is still a relatively new disease and despite an impressive and internationally coordinated research programme, the full range of its long-term consequences remain unknown. Uncertainty has been there from the beginning with COVID-19. At the outset of the pandemic there was no shared understanding of the way this novel coronavirus affected those who had it. People presented a wide range of symptoms, including fever, headache, shortness of breath. Gradually, reports began to emerge, first from China, then from Iran, Italy, Germany, France, then from the U.K. and the U.S., following the pattern of spread of the virus, of an unusually high incidence of people reporting a sudden loss of smell and taste. [15] [16] [17] People exhibiting these symptoms, if they were tested, were typically confirmed as having SARS-CoV-2. Many of them were healthcare workers. [18]

We now know that loss of smell is one of the most prevalent symptoms of COVID-19 [19] [20]. However, many countries did not officially recognize smell loss as a coronavirus symptom – often the only symptom - until the pandemic was widespread. Though it took weeks for the WHO and the United States CDC to recognize it, it even longer in the U.K. for Public Health England to acknowledge that change of smell or taste should be added as a third officially recognized symptom. Moreover, this recognition was not without considerable resistance. The announcement by PHE to acknowledge loss of smell as a symptom was made on 18 May and yet as early as 20 March in a joint statement of the British Rhinological Society and ENT-UK, Professor Claire Hopkins and Professor Nirmal Kumar recommended that loss of smell be treated as a marker for those who may have been carrying the virus undetected. [21] A letter to the BMJ on 1 April, 'Wake up and smell the symptom' urged Government medical advisors to take seriously the possibility that people with smell loss could be carrying the virus and spreading it to others in healthcare settings.[22] Yet it took a sustained campaign by ENT clinicians, sensory scientists, healthcare specialists and patient advocates to gain recognition of a symptom that is now known to be the most effective predictor of COVID-19.

The initial lack of response to reports of smell-loss was not merely due to uncertainty about the evidence, or shifting information in a rapidly changing research landscape; rather, it points to pre-existing issues brought to light by COVID-19 about how patients and general practitioners understand and respond to symptoms, and how information is shared or exchanged through patient advocate groups and between those groups and healthcare workers. The current pandemic and its aftermath offer an opportunity to learn lessons about vital information sharing between patient groups and medical practitioners, as a means to increase trust in the medical profession, to build support and shape priorities for scientific research. It should also ensure that patients can access appropriate care and support.

Section 3. Long Covid and patient experience post-pandemic

Recent reports on the management of conditions brought about by post-acute COVID-19 illness, known as 'Long Covid' have emphasised a broad range of symptoms experienced by those recovering from the illness, but so far these discussions have left out symptoms such as loss of smell and taste.[23] Clinicians and medical researchers have warned that olfactory dysfunction should not be overlooked in the post-acute phase of the illness. [24] Of interest, is the high incidence of parosmia among those recovering from COVID-19-induced hyposmia or anosmia.

Currently, 50% of COVID-19 sufferers recover sense of smell within 2 weeks, but 10% see no recovery at 3 weeks, and 3% no recovery at all at 6 months - given the case incidence this is a large number of patients with complete ongoing loss. There are also large numbers with incomplete recovery. The much less well-known condition of parosmia is seen in 43% of cases. Parosmia produces a strikingly distorted sense of smell (mostly off-putting odours) in familiar items and food products. 1 in 5 show no improvement at 6 months post infection and this persistent olfactory dysfunction is the biggest driver of referrals and patients in ENT clinics. [25]

Healthcare services offer little information to those facing what is likely to become a chronic and distressing condition. A highly representative post on Twitter from a sufferer of parosmia who did not have anyone to turn to – not unusual among people afflicted with such post-viral symptoms - states:

> I thought having anosmia was bad, but parosmia is horrendous. Food smells and tastes like fruity sewage! Constantly battling with nausea and no desire to eat.
>
> I feel sad and depressed and distanced to the world as it used to be. Not being able to smell the most mundane things, like the rain or my boyfriend's perfume. Not being able to participate socially like I used to.

> This is terrifying, how long does this stage [parosmia] last
>
> Really feel like no one understands the impact it’s had on my mental health.
>
> I was crying everyday, and finally called my doctor for some anti-depressants.

So far basic research into, and treatment of, parosmia are still somewhat limited:

> There are few therapeutic options available to treat parosmia, but patients will need support and advice, and this is an area where further research is urgently required.[26]

However, research interest is growing; largely due to the work of patient groups, and the role they play, which, as we shall demonstrate, is essential to tackling the larger social issue. One patient comment highlights a theme to be taken up below:

> We just have to keep going back to the GP until they realise that we are the research. we need to be counted.

GPs are less likely to understand the condition than they are the acute and officially recognised symptoms of hyposmia or anosmia. So, once again, there is a danger of failing to recognise patients’ concerns and in doing so overlooking some of the long-term effects on patient’s quality of life. People in this category face reduced access to care and support, and, if their needs are not addressed, there is a risk of increasing the burden on healthcare services and reducing trust in them.

Greenhalgh and colleagues’ otherwise excellent BMJ article on the management of post-acute COVID-19 emphasised the broad range of symptoms experienced by patients with what has been termed Long Covid but failed to mention smell or taste disturbance.[27] A patient led project evaluating COVID-19 recovery with a survey found that loss of smell and taste was reported by more than 50% of respondents [28] ; loss of appetite and nausea even more frequently.[29] The terminology used in such surveys, “loss of smell or taste,” very probably underestimates the extent and health consequences of parosmia. [30] Altered sense of smell and taste was only recently added to the list of symptoms captured in the JoinZoe COVID symptom tracker, and smell and taste loss and parosmia has been overlooked in the digital NHS My COVID Recovery programme, until this was addressed by members of our group.

It is salutary to look at patient comments expressed in 2020 on the AbScent Facebook Group after ENT consultant and researcher, Professor Claire Hopkins put out a call to hear more about patients' experiences:

> You wonder how on earth an ENT specialist would not have heard of this horrible condition of anosmia and that its obviously connected to COVID! You do feel ignored
>
> Seems crazy that the NHS has not distributed information and educated ENT specialists about this
>
> Doctors just flat do not know anything about this problem
>
> Smell loss is not new to ENT but until COVID it was not considered
>
> I called the COVID helpline and they had no idea what I was talking about. It's so frustrating
>
> There's nothing the GP can do and no-one understands unless they are going through this
>
> I asked my GP for a referral to ENT and an MRI – he laughed at me down the phone
>
> Parosmia is not taken seriously - GP even suggested it might be psychosomatic

The general worry raised here is that if symptoms like anosmia are followed by parosmia for many people recovering their sense of smell, then when the coordinated efforts of the healthcare system and emergency response shifts from acute symptoms relevant to disease control, to chronic conditions that follow from them, conditions like these (and others in the cluster of symptoms being described as Long Covid) may go back to being neglected. If so, there will likely be a resultant negative impact on a large proportion of society, with attendant consequences on trust and confidence in healthcare services.

A similar story can be told with respect to FND. Neurologist Mark Edwards:

> One important and consistent research finding is that physical triggers are very common at the onset of symptoms; they are seen in 80% of patients. These physical triggers cover a range of “health events” from injuries, operations, drug reactions and physical illnesses. Of course, such phenomena have both a physical and psychological component to them (e.g. the physical symptoms occurring from a car accident and the psychological experience of having the accident and experiencing the symptoms). This is a pattern of triggering of FND that is highly consistent across cultures and throughout recorded medical history. This is where, in my opinion, there is a significant overlap between FND and the phenomenon of “Long Covid”. It is entirely expected that a physical illness of this sort should be likely, in a proportion of people, to trigger the development of persistent symptoms which, arguably, relate to dysfunction in the system that underlies FND, rather than relating directly to damage caused by the virus.
>
> It would be expected that persistent symptoms would to some extent mirror those of the infection itself (e.g. be dominated by fatigue), but would then likely develop in scope and escalate over time, rather than showing the pattern of slow improvement/plateauing seen usually after structural damage. One would expect more women to be affected than men, and for those aged 30-50 to be at highest risk. One would expect sufferers to be, on average, more physically active than the general population, and to include a higher proportion of people involved in “extreme” physical activity.

As a clinician and researcher, Mahinda Yoga expresses the following hope:

> Our understanding of “long covid” is still at an early stage. However, it is possible that symptomatic patients with long covid will fall into one of three groups; those with demonstrable end-organ damage on conventional testing, those with symptoms akin to a post-viral syndrome, and those with “medically unexplained symptoms” that may have some pathophysiological parallels with functional neurological disorders. It is therefore possible, because of its prevalence and significant media attention, that “long covid” may shine a light on the out-dated, dualistic notions of health, and the importance of paying more clinical and scientific attention to functional neurological disorders and symptoms. At the very least, “long covid” will hopefully put to bed the notion that patients with symptoms and signs but no demonstrable abnormalities on conventional testing, are not worthy of our care or research.

It is only possible to improve healthcare outcomes and avoid the social cost of patients not receiving the care and support they need if lessons can be learned in the post-pandemic period. There are ways society can address the problem of increased burden on healthcare services, of patients feeling frustrated that their symptoms are not recognised, and the long-term cost of not managing chronic conditions that adversely affect quality of life. The signs of a different way of working have appeared during the pandemic, and are a result of increased attention to symptoms, support groups meeting patients' need for information through the work of patient advocates and the renewed efforts of researchers to understand the mechanisms underlying the range of symptoms COVID-19 patients present. After documenting these steps, we will turn to the final piece of the jigsaw, which is the need for better information and training to reach GPs and other healthcare providers.

This new pattern of working can be glimpsed in the new directions of FND research. Neurologist, Mark Edwards again:

> The last 10 years have seen major developments in diagnosis, ways of explaining the diagnosis successfully, and how to organise effective treatment in FND. These developments are likely to be highly relevant to people with long Covid. My hope for people with FND, including those where symptoms are triggered by Covid infection, is that we can avoid the physical/mental splits which have so bedevilled progress in this area for centuries, and can instead adopt a scientifically principled and holistic approach to helping people with this very common and disabling illness.

Similarly, the coronavirus pandemic has cast greater light on hidden disabilities such as anosmia that can result from post-viral infection. There is greater awareness in the medical profession, among scientific researchers and in the wider public of this condition and its consequences for our everyday lives. The rapid rise in cases of sudden onset anosmia during the pandemic and the possibility that studying its causes could provide clues to the way SAARS-Co-V2 infected its hosts led to a massive research effort among olfactory scientists and a speeding up of normal ways of working.

In response to the original reports of the loss of smell and of taste in people who had tested positive for COVID-19, a group of international smell and taste researchers united to form the Global Consortium for Chemosensory Research, first of all to study how, when and why this was happening, what it could tell us about the Coronavirus and to conduct surveys and publish scientific research. The GCCR has over 600 members in 62 countries and comprises scientists, clinicians and patient advocates. Through the extensive reach and multidisciplinary nature of its members, the GCCR was able to coordinate world-wide crowdsourced research to understand the reports of the chemosensory issues related to COVID-19. Its first publication, 'More than smell - COVID-19 is associated with severe impairment of smell, taste, and chemesthesis' had 94 authors from all of the three communities of patients, clinicians and researchers among its membership.[31]

This coordinated research effort could not have happened without the involvement of patients and clinicians providing accurate information and commenting on one another's findings on the membership platform. Researchers working on olfactory and chemosensory science had never experienced that level of global and cross-sector collaboration before.

The research collaboration on smell loss has been extensive but as yet, far less attention has been given to the developing spread of parosmia among those recovering from COVID-19 and once again, it is the reports from patients and the rise in cases noted by clinicians that will spur the research effort in this area.

The lessons that different sectors' responses to COVID-19 have brought to light point to new opportunities for a coordinated approach to patient care and to tackling the long-term effects of COVID-19 on society without placing an undue burden on the health service. Crucial to this new configuration of support, care and scientific advance is the role of patient groups. Two such U.K. groups with close connection to health care professionals with ENT specialisms are AbScent, a charity set up to help people with smell loss or smell dysfunction, and Fifth Sense, a charity created to support people with smell and taste disorders.

Section 4. Patient Groups

Fifth Sense is a membership organisation established in 2012 to support anyone suffering from a taste and smell disorder. It became the U.K.'s first charity for those with anosmia who could share experiences, gain information and be offered advice that is developed through partnerships with clinicians, researchers and others whose work is based around taste and smell. It sees its function as ‘providing a signpost to potential diagnosis and treatment, and playing a leading role in educating society on the huge role that smell plays in our lives’ (Founder, Duncan Boak).

AbScent is a registered charity that provides support and trusted information to those suffering from anosmia or smell disorders. Its trustees are from the fields of medicine and sensory research. It offers support and provides information and the latest research based on peer-reviewed scientific evidence. In addition, it is responsible for a number of interactive Facebook groups moderated by its Founder, Christine Kelly. During the pandemic it ran webinars with clinicians and scientists who reported to members on the latest findings using language pitched at a lay audience.

The key functions of these two charitable organisations is to provide support and reliable information to patients and others, which connects them to the latest scientific research and clinical guidance. At the same time, information from patients about the course of their condition informs clinicians and researchers and provides vital clues about the effects of the virus.

Patient groups exist for those who find their way to them. However, many others speak out on social media about their desperation in not receiving help for a condition they find profoundly distressing. (Permission was obtained to quote these comments):

With little information available during the beginning of the pandemic, and the UK government slow to respond to calls for recognising smell loss, patients took to Facebook. The original AbScent group had a large influx of new members in February and March of 2020, which necessitated the opening of a new COVID-19 group. This group was established on the 24th of March and grew to 14K members by November.

This patient support group became a centre recognised for its high standard of information. With many members from the GCCR at the outset, and many clinicians and researchers who came in through links on Twitter, the group became a two-way information exchange: providing sound information and advice to patients based on the latest understanding of the science, and also allowing researchers access to patients for their own research purposes.

This patient/researcher interaction was constantly monitored and reviewed to ensure maintenance of standards. Patients felt they were being helped by being able to participate in research. Researchers had confidence that this engaged group would participate in their surveys and questionnaires. As an example, a request for short answers to a research question by one clinician elicited over 450 responses.

Despite large numbers, the group is heavily moderated. This is part of its success. Some of the large Long Covid support groups are now collapsing under their own weight due to lack of moderation and “wild west” atmosphere. Scientific rigour in conversation there is not well screened. Important topics, such as the coming vaccine, require careful handling for this reason.

In asking how patients can best be served, it is important to look beyond the role of rhinologists. Outpatient appointments with ENTs will be necessary to rule out more sinister causes of smell loss, but where recovery from damage to the olfactory nerve is concerned, the best help and support comes from sources such as patient groups. The non-medical interventions recommended by the BRS and ENT UK include smell training and nasal rinsing as well as the use of some supplements. Suggestions for food management for parosmia cases is especially important. Finally, an understanding of, and active intervention for, decline in well-being is essential.

> I was very glad to find this group because although what we are experiencing is awful, it helped me to feel less scared about what is happening
>
> don't give up hope lots of us including me in the same position...this group will listen and support

It is clear that online patient communities created by Fifth Sense, and those in AbScent whose forums are moderated by patient advocates working closely with ENT clinicians can ensure that patients receive accurate scientific and clinical information while at the same time conveying vital information to researchers and clinicians about patterns and occurrence of symptoms seen in that community. It is a handy corrective to scientists working on hypotheses that provide neat explanations but which do not cover the actual patterns of change or distortion in olfactory dysfunction.

The last point has a wider significance and has a more general application. It will be important to leave room for nuance in the attempt to pin down and characterise the symptoms of Long Covid if we are to ensure research efforts remain sharply focused and if we are to ensure sufferers receive the care and support they need. To do this, we need reliable forums for patient groups to work with scientists and clinicians, and to participate in the research as citizen scientists.

Section 5 - Important principles of productive collaboration

I. *Trust*

Mistrust is a key concern for those seeking information and an important issue for those who aim to ensure that relations between patients, clinicians and researchers remain effective to address. It is particularly important to make sure that epidemiologists, GPs and even Ear Nose and Throat specialists are better educated about olfactory dysfunction and that clinicians, researchers and patient groups are kept informed by one another.

For example, at a time when mass testing was less like than it is now, suggestions were made in some quarters that smell tests could be used to screen for COVID-19 at airports and in public places. Such suggestions revealed a misunderstanding of the occurrence and duration of olfactory problems, and as a result what appeared to many as a useful strategy ran the risk of penalising those who had existing olfactory dysfunctions, pre-COVID-19. In a reply to a suggestion of widespread smell testing by Professor Tim Spector's group, Professors Claire Hopkins and Barry Smith pointed out that such a policy was likely to produce false positives in elderly populations where a high-percentage of people are functionally anosmic as a result of ageing, and would pick up on those recovery from COVID-19 with persisting olfactory disorders who would be no longer infectious.[32] Besides, individual differences in threshold for odour detection would render any simple mass testing kit ineffective and show that smell testing for COVID-19 has limited application.

More worryingly, is how health service professionals have interpreted the significance of patients’ symptoms. Here, from the AbScent Facebook group here is report of a dentist’s response to hearing the mother of one of his child patients had still not recovered her sense of smell:

> My eldest had to get a tooth out yesterday. Dentist went through a Covid check and when I was honest that have parosmia and clear it was linked back to end of March they wouldn't let me attend with him. He's only 10 and they really hurt him, he and my husband basically in shock last night - apparently he was screaming and begging them to stop (and we have referral to hospital to finish the job) Feel horrible, I could have been there with him if I'd just kept my mouth shut. Why won't this just go away???? And why am I stupidly honest?!?!? Another bad day

The lack of confidence in healthcare workers is eroded by such misleading responses. By contrast, as patient groups have developed they have built and encouraged trust, and crucially have become an information exchange between the patients and the clinicians/researchers, the latter helping to ensure that patients receive reliable information while the former help to inform and drive priorities in clinical practice and scientific research. These two-way flows of information can play an important part in ensuring there is widespread trust in medicine and science and that patients receive the support and care they need and can find ways of managing their conditions outside of the confines of primary healthcare. Such patient groups become not only advocates for diagnosis and treatment but for sound and trusted information exchange and for trust and support of the medical and scientific community. However, this relies on the latter communities being appropriately responsive to, and in connected with, patient groups.

One of the barriers to such collaborative working and the establishing of trust in the medical community and primary healthcare services is the lack of information and training needed to update GPs and other healthcare workers on conditions like anosmia, parosmia and FND. In the latter there is evidence that training helps engagement and satisfaction of both participants in the clinical encounter. [33] In the case of olfactory dysfunctions the charity AbScent works with the British Rhinological Society, through its president, Professor Claire Hopkins, to provide online training materials for GPs and ENT clinicians about the symptoms, diagnosis and treatment of olfactory disorders. Similarly, the charity Fifth Sense works with an ENT consultant to provide updated materials for patients and healthcare workers. These information flows are vital for a joined-up service that supports patients, improves clinical practice and drives scientific research for the benefit of everyone in society.

II. *Governance*

The recent responses to the pandemic have highlighted the need to capture and study symptoms of a new disease and to highlight symptoms of post-viral infections that pre-dated the coronavirus outbreak; and as we come out of the pandemic there is increasing evidence of persisting conditions such as chronic fatigue and olfactory dysfunction. The effect on quality of life can be profound and those suffering will often attempt to access healthcare services to seek prognosis and treatment. At present, treatments may not be available and many patients will feel frustrated with the way their conditions are being handled and may press for further referrals to specialists. This is likely to put additional pressure on the healthcare system while leaving patients unsatisfied and without care and support. There is good reason to think this predicament for patients and for healthcare services can be avoided if steps are taken to ensure that patients can seek reliable advice by being put in touch with patients' groups who can help them understand and manage their conditions even if no medical treatment is immediately forthcoming. They can also be encouraged to contribute valuable information to researchers who will help undercover the mechanisms underlying their conditions, the stressors that may aggravate it, and the likely avenues of research that could point towards future treatments.

In the case of smell loss, the most effective intervention currently available, as shown in scientific and clinical studies is olfactory training, or smell training. Routinely sniffing each of four different essential oils every day for three months has shown demonstrable improvements in hyposmia and anosmia.[34] This relatively low-cost intervention need not be offered as an outcome of healthcare appointments, although it is recommended by ENT clinicians who are aware of recent scientific literature, and is more likely to be explained and advocated by reliable patient groups like the charities mentioned above. A better spread of information between patient advocacy groups, healthcare workers and researchers would ensure that such guidance could be provided in leaflet form or by easily accessed online videos and made readily available to the portion of the public who are affected. It would also ease the burden on existing healthcare services and help to eliminate unnecessary appointments and referrals. For example, a number of patients with COVID-19 related anosmia awaiting ENT review by one of the authors report that they no longer feel that they need an appointment after being signposted to the Nosewell project (AbScent.rog/Nosewell), created by AbScent and the BRS. At a time when all clinical services face a huge backlog due to the cancellation of elective work during the early stage of the pandemic, resources that reduce healthcare utilisation in the large cohort of patients directly affected by COVID-19 will help restore access to care for other conditions that have been indirectly impacted.

The above leads us to conclude that a pressing issue for the assessment and treatment of the smell and taste loss associated with Long Covid, and for Long Covid in general, is the training of health professionals to enable them to engage and help patients.

The rational coordination of different agents working together must not be left to chance. So far, it is as a result of a few interested clinicians and researchers working with patient advocates, or as a result of emergency measures such as the setting up of the Global Consortium of Chemsensory Researchers in the face of pandemic that people have come together. Patients report in the case of smell loss:

> It feels like it will be years before medical knowledge catches up to what we are experiencing. And that is a strange place to be.

A better system of governance could and should be designed to encourage and formalise the working relations that connect patient groups with healthcare workers and researchers, to ensure patient groups are reliably informed and equipped to offer good advice and guidance and to ensure that information from patients working with clinicians and researchers is fed back into informing and training healthcare workers to deal with the conditions represented by those patient groups. The widespread communication of reliable information is vital in a time when those dissatisfied with the lack of explanation or support for their condition can search online and receive misleading information that reduces trust in science and the healthcare system. A properly conceived way to ensure effective information flow and to facilitate collaboration between the scientific, healthcare and patient communities is the connective tissue needed to alleviate increasing demand for healthcare provision, to ensure appropriate care and support is available to help manage conditions for which no treatment is yet available, and to keep focus after the current pandemic subsides on avenues of scientific research that may produce breakthroughs in understanding. Such a system of governance will also bolster trust and confidence in science and medicine and allow society to have a greater stake in contributing to scientific research.

iii. *Inequalities in vulnerability, exposure and reach: consequences for wellbeing*

The COVID-19 pandemic magnifies and widens inequalities amongst different populations. A recent report to Independent SAGE on COVID-19 and health inequalities reveals that illness and death associated with infection are as much as twice as likely to occur amongst more deprived communities. [35] Co-morbidities, occupational exposures, social crowding, the lack of sickness benefits and lack of access to health care services are socially and economically patterned. Inequalities refer to differences in exposure to the social determinants of health which include the conditions under which people are born, grow, live, work and age. Access to beneficial and health enhancing environments favour better health outcomes and fewer complications.[36] Those living with fewer economic resources, poor housing, inadequate diets, pre-existing conditions, physical hazards through work, environmental exposures such as air pollution are known to be more ‘at risk’ of health complications and ‘sensory inequities’ (unequal access to healthy sensory environments).[37]

All of the above has recently led the editor of The Lancet Richard Horton to label COVID-19 a ‘’syndemic’, deploying the term used by Singer at al in the 1990s to describe how the HIV epidemic disproportionately affected those with lower socio-economic and BAME communities in North America. Singer recognised that “a set of closely interrelated endemic and epidemic conditions (eg, HIV, TB, STDs, hepatitis, infant mortality, drug abuse, suicide, homicide, etc.), all of which are strongly influenced and sustained by a broader set of political-economic and social factors”. As Horton puts it:

> A syndemic is not merely a comorbidity. Syndemics are characterised by biological and social interactions between conditions and states, interactions that increase a person's susceptibility to harm or worsen their health outcomes. [38]

In England, various studies have demonstrated that COVID-19 rates are higher in BAME communities, and in those living in deprived areas.[39] A higher burden of pre-existing illness (such as diabetes, respiratory conditions and eating disorders) and conditions such as food insecurity also increases the risk and potential severity These interactions also have a direct impact on smell, taste and eating. For example, evidence from Spain reveals that 1 in 3 people with eating disorders (such as bulimia, anorexia, binge eating disorder) have experienced worsening symptoms with the pandemic. Coupled with evidence of smell and taste disturbance with COVID-19 one participant comments:

> This situation is hard enough but throw an eating disorder into the mix and I don’t even know where to start. Eating and caring for myself during good times is a struggle. The last 5 weeks [with anosmia and parosmia] were becoming unbearable

Olfactory dysfunction may contribute the emergence of a cluster of problems in a variety of ways. Olfactory impairments are strongly associated with neurodegenerative diseases and ageing thus putting these populations at particular risk.[40] Air pollution has been strongly associated with olfactory impairment and there is evidence that sensory inequities may pre-dispose some populations to greater exposure and severity of COVID-19 complications. [41] Although still at an early stage, strong evidence is emerging that exposure to particulate matter, particularly PM 2.5, correlates to ACE-2 receptor overexpression and more severe COVID-19 infection and vulnerability to infection. [42]

It is thus of vital importance, in considering the health care provision and health care research of those affected by COVID-19, that ‘reach’ is a feature of productive collaboration. That is, we must ensure that those most vulnerable, most badly affected and least able to access health services and information are also consulted, considered and included in planning responses.

Section 6. Next steps

The above survey has attempted to capture the emerging picture of the interaction of the COVID-19 patient with the health care system. In particular we have looked at the potential stress points of this interaction by highlighting the parallels with FND and other persistent physical symptoms, and with what we know about the treatment of smell and taste disorders. Equally pertinent is the emerging picture of how health inequalities are playing out in the experience and treatment of COVID-19, and how the voices of the minorities, the poor and the marginalised are often not accounted for in both health care and health care research.

From all of the above we conclude that what is urgently needed is a patient and participant lead development of training for health care professionals. This is needed to avoid some of the pitfalls that patients with FND and smell and taste disorders currently experience. It is clear from both these conditions that training makes a difference to the experience of both the patient *and* the clinician. As such we propose the following

AIM – The development of a health professional training intervention to improve the treatment of log COVID-19 symptoms including smell and taste dysfunction.

To achieve the improvements of collaborative working among the three communities of patients, clinicians and researchers, discussed in this survey we would suggest the following programme of research:

Objectives:

- Work with patients and other stakeholders to identify their needs with regard to health care professionals.
- Work to extend the reach of the stakeholder involvement to poor, marginalised and minority communities.

- Work with health care professional stakeholders to assess their training needs, targeting in particular the clinical groups (eg ENT, Dietetics, GP, SLT, Nurse) who routinely will encounter smell and taste dysfunction.
- Development of health professional training packages based on the above
- Delivery of a pilot health care professional training programme with an embedded process evaluation of clinician self-efficacy and confidence; intervention uptake/translation into practice and impact on patients.

Methods:

This work would be led by patient and public involvement. We already have a highly engaged group of Long Covid smell and taste loss sufferers in both the Facebook and GCCR forums who have already suggested ways in which they wish their clinical care to be improved. We would formalise this work by conducting PPI led focus groups with patients and clinicians to ascertain training needs. We would then develop training packages with them, and trial this in a small pilot to study the barriers and facilitators to assess intervention uptake.

Projected Outcomes:

A scalable brief training in smell and taste loss dysfunction assessment and treatment CPD module that could be delivered online to frontline health care staff.

Section 7 Conclusions

The picture emerging of the understanding and treatment of COVID-19 related smell and taste loss, and long Covid in general, has a strong family resemblance to what is already known about persistent physical symptoms, FND and smell and taste loss in other conditions. These conditions are marked by stigma and disbelief, invisibility, poor treatment and lack of health care professional training. We believe that this situation is remediable, but only with urgent action to put together health care professional training.

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